

2007

32nd
Institute on
Rehabilitation Issues

Rehabilitation of Individuals with Autism Spectrum Disorders



32nd IRI 2007

INSTITUTE ON REHABILITATION ISSUES

**REHABILITATION OF INDIVIDUALS
WITH AUTISM SPECTRUM DISORDERS**

**REHABILITATION SERVICES ADMINISTRATION
U.S. DEPARTMENT OF EDUCATION**

**THE COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL
REHABILITATION**

**THE GEORGE WASHINGTON UNIVERSITY
CENTER FOR REHABILITATION COUNSELING RESEARCH AND
EDUCATION**

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Dew, D. W., & Alan, G. M. (Eds.). (2007). *Rehabilitation of individuals with autism spectrum disorders* (Institute on Rehabilitation Issues Monograph No. 32). Washington, DC: The George Washington University, Center for Rehabilitation Counseling Research and Education.

The contents of this IRI document were developed under a grant (H264A040302) from the U.S. Department of Education's Rehabilitation Services Administration awarded to The George Washington University. However, these contents do not necessarily represent the policy of those agencies, and endorsement by the federal government or the university should not be assumed.

TABLE OF CONTENTS

PRIMARY STUDY GROUP MEMBERS	v
PREAMBLE	vii
INTRODUCTION	xiii
CHAPTERS	
1 INTRODUCTION TO AUTISM SPECTRUM DISORDER	1
2 TRANSITION PLANNING FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS.....	15
APPENDIX A: PLANNING FOR POSTSECONDARY EDUCATION AND TRAINING.....	40
APPENDIX B: PLANNING FOR VOCATIONAL DEVELOPMENT	49
APPENDIX C: TEN THINGS YOUR STUDENT WITH AUTISM WISHES YOU KNEW	50
3 ACCESSING THE VOCATIONAL REHABILITATION SYSTEM	55
APPENDIX D: FINDING A JOB AND DESIGNING ACCOMMODATIONS...	86
4 SUPPORTING SUCCESSFUL EMPLOYMENT	89
APPENDIX E: SELF-ADVOCACY AND DISCLOSURE	115
5 CHALLENGES AND RECOMMENDATIONS	119
APPENDIX F: STANDARDS OF THE NATIONAL ASSOCIATION FOR RESIDENTIAL PROVIDERS FOR ADULTS WITH AUTISM	135
APPENDIX G: MODEL FOR TRAINING: VOCATIONAL REHABILITATION ISSUES FOR PERSONS WITH AUTISM SPECTRUM DISORDERS	137
APPENDIX H: GLOSSARY	139
STUDY QUESTIONS.....	149

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PREAMBLE

By Donald R. Uchida

Statistical information generated by the Rehabilitation Services Administration (RSA) for fiscal years (FY) 2003 to 2005 indicates that people with autism are severely underserved in terms of achieving employment outcomes by the state/federal vocational rehabilitation (VR) program (see Table). Please be aware that there is a difference between autism and autism spectrum disorder (ASD). While the term autism, used by the RSA, has a much narrower definition, the only data available were for autism rather than ASD.

Although the number of individuals with autism achieving employment outcomes increased over the 3-year period, those with autism were a very small proportion of total closures—less than 0.6% in 2005. Of equal or greater concern, however, is the ratio of unsuccessful to successful closures for people with autism. In 2005, unsuccessful closures were still about 1½ times greater than successful closures. While the RSA defines individuals served as those having an implemented plan, the primary study group wanted to include all closure types to see if there were any systemic or programmatic barriers in the VR system specific to individuals with ASD. Those barriers are addressed in subsequent chapters of this document.

Table

Successful and Unsuccessful VR Closures for Individuals with Autism, 2003 to 2005

Fiscal year	Status 26		Status 28	Status 08/30	Proportion: unsuccessful to successful closures
	Total	With autism	With autism	With autism	
2003	217,557	719 (0.33%)	453	653	1.54 (1106:719)
2004	213,431	948 (0.44%)	612	788	1.48 (1400:948)
2005	206,695	1,141 (0.55%)	696	993	1.48 (1689:1141)

Note. Status 26 represents individuals who successfully achieved an employment outcome as defined by the RSA; Status 28 represents individuals who had plans and had received some services but were not able to achieve an employment outcome; Status 08 represents individuals who had no employment outcome based on applicant status, trial work/extended evaluation, or order of selection waiting list; and Status 30 represents individuals who had no employment outcome after eligibility determination but prior to the development of a plan or implementation of an approved plan. The proportion of Status 28, 08, and 30 closures to Status 26 closures represents the proportion of unsuccessful to successful cases. Source: RSA, 2004, 2005, 2006.

In addition, the Centers for Disease Control and Prevention (2006) reports that the incident rate for ASD in the general child population is now in a range reaching 1 in 166. This increase, which has already made an impact on the elementary and secondary school systems, will in turn increase the number of ASD referrals to the VR system as these students with ASD transition from school to VR and other adult services.

Supported employment has been identified as a potentially successful strategy in assisting individuals with ASD to achieve employment outcomes. While there may be varied definitions of supported employment and its concepts and strategies, for the

purpose of this document the definition in the VR federal regulations is utilized:

Supported Employment means:

Competitive employment in an integrated setting, or employment in integrated work settings in which individuals are working toward competitive employment, consistent with the strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice of the individuals with ongoing support services for individuals with the most significant disabilities—

(A) For whom competitive employment has not traditionally occurred or for whom competitive employment has been interrupted or intermittent as a result of a significant disability; and

(B) Who, because of the nature and severity of their disabilities, need intensive supported employment services from the designated State unit and extended services after transition as described in paragraph (b)(20) of this section to perform this work. [34 CFR 361.59(b)(53)]

Extended services are defined as:

(20) Extended services means ongoing support services and other appropriate services that are needed to support and maintain an individual with a most significant disability in supported employment and that are provided by a State agency, a private nonprofit organization, employer, or any other appropriate resource, from funds other than funds received under this part and 34 CFR part 363 after an individual with a most significant disability has made the transition from support provided by the designated State unit. [34 CFR 361.5(b)(20)]

The primary service in supported employment is job coaching, which is provided by a job coach. A job coach is a person on site to help the individual with a severe disability learn and perform a job. This is a very simplistic definition of a rather complex and diverse set of tasks and duties. The job coach must first assess or have

knowledge of the individual's skills, abilities, and functional limitations. Next the coach must find, develop, or carve from an existing position a job that the individual with ASD can perform successfully. The job coach must then learn the job, be able to break down the job into teachable increments, and train the individual to do the job or at least part of it.

In addition to the specific job tasks, the job coach is responsible for teaching the “soft skills” needed for success in the workplace. Those skills include but are not limited to appropriate behavior, appropriate dress, timeliness, personal hygiene, respect for coworkers and supervisors, appropriate communication, and taking on responsibility. Once all the issues listed above are addressed, it is the expectation that job coach intervention will “fade,” allowing the individual to exit the VR system and enter into extended services.

The lack of extended services, also called long-term support, has been identified as one of the major barriers to the successful employment of persons with ASD. Funding cuts to state developmental disabilities agencies as well as the reduction in Medicaid waivers has restricted the ability of VR agencies to utilize supported employment.

Federal regulations require the VR agency to identify the long-term support agency, funding source, or other resource that will provide the extended service, including a description of the basis for determining that the extended services are available. If it is not possible to identify the source of extended services at the time the individualized plan for employment is developed, the agency must describe the basis for concluding that there is a reasonable expectation sources will become available [34 CFR 362.11(g)(3)(i)].

At the onset of the 32nd Institute for Rehabilitation Issues, the prime study group was given the following list of objectives, with the expectation that the document would address each of them:

- Outlining the state of the science on ASD: providing an overview of the importance of early intervention and treatment on social development, academic and employment, and independent living outcomes

- Understanding the continuum of the disorders and strategies for increasing awareness
- Enhancing the implementation of informed choice throughout the VR process
- Identifying issues and conditions for effective transition from school to work, training, or postsecondary education
- Building effective partnerships between academic, training, health, housing, and other community-based social programs and agencies, including developmental disability providers
- Improving employers' understanding of ASD
- Promoting holistic VR: integrating family, community, and social supports to improve employment outcomes
- Improving VR counselors' and employers' skills, competencies, and knowledge for increasing accessibility and employment opportunities and improving job accommodation
- Describing evidence-based strategies for effective job development, placement, and retention

We, the primary study group, sincerely feel that the objectives of the 32nd Institute of Rehabilitation Issues, *Rehabilitation of Individuals with Autism Spectrum Disorders*, have been addressed. We hope that you, the readers, will find the document a useful resource and tool.

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INTRODUCTION

By Ruth Christ Sullivan

Until recently, vocational rehabilitation (VR) agencies rarely provided services to individuals with autism and/or autism spectrum disorder (ASD). Even now, few universities offer coursework to prepare VR professionals for the significant challenges they face when an adult with autism shows up in their office requesting services.

Generally speaking, many, if not most, VR personnel have little or no formal preservice education that would give them the skills to appropriately serve this growing and seriously neglected disabled population of U.S. citizens.

Through no fault of their own, VR counselors find themselves in the same situation as other professionals who, earlier, were impacted by this mysterious and enigmatic disorder but had no prior training. Because autism typically manifests itself in the first year of life, the professions that serve infants and young children were among the first to come forward with information and treatment. The first article on autism was written in 1943 by a Johns Hopkins pediatric psychiatrist, Leo Kanner, who began to see these unusual children in his clinic.

The following is a brief overview of how autism made its way to VR.

Background

Individuals with the diagnosis of autism and their advocates have had decades-long battles for recognition as citizens worthy of the public's support. Since the civil rights movement in the 1950s, 1960s, and 1970s, more and more disenfranchised, marginalized groups of people have come forward to claim discrimination and demand equal access to our country's noble premise that "all men are created equal" and that "liberty and justice for all" applies to them too.

In the field of developmental disability (DD), blindness was among the first to be recognized as deserving national support, mainly because of Helen Keller's famous public life. She dramatically demonstrated that, with proper support, she could participate in normal society. In 1936 the U.S. Congress passed the landmark Randolph-Sheppard Act. It set aside funds to assist other U.S. citizens who, like Ms. Keller, are blind and deaf.

Forty more years would pass before Congress would fund significant supports and services for other DDs, like mental retardation, cerebral palsy, epilepsy, and Down syndrome.

The DD Act of 1970 was landmark legislation for this group of individuals, but unfortunately, autism was not included in it. The definition of DD included "mental retardation, cerebral palsy, epilepsy and others as defined by the Secretary" of the Department of Health and Human Services). It wasn't until several years later that, after considerable effort by the Autism Society of America (formerly the National Society for Autistic Children), autism was added as a specific clinical entity.

As society increasingly took on more responsibilities for the care of people with disabilities—providing services that previously were totally the duty of families—it was inevitable that the professionals who serve them would have to learn new skills. Typically, the easiest and least expensive to serve were first allowed into the public system, such as education. Students with autism were typically the last admitted after the mandate.

Since 1975 when the Education for all Handicapped (now Individuals with Disabilities Education Act) legislation was enacted by Congress, school-aged children with disabilities, including those with autism, had a right to a free and appropriate education. Special education was a new field, and the country's public school systems and university departments of education were challenged to meet the sudden influx of disabled students who now sat in the nation's classrooms. More often than not, teachers did not have formal training to meet their needs.

Gradually the universities began to offer special education degrees. These days it is expected that public schools will have appropriately trained faculty teaching pupils with disabilities. But, even today, very few universities are offering courses in autism, and even fewer offer a practicum in this special area.

The specialty of autism is relatively new. The school system now has the largest group of disability personnel, many of whom now have some experience in autism. However, once individuals with disabilities are out of school, at age 22 and earlier in some states, no one entity in our society provides for their needs, especially for those with a highly unusual, lifelong disability like autism. And unlike school services, there is no entitlement for adult services.

Before 1981, families had two choices: keep the young person with a disability at home with little or no services or put him or her in a state mental institution.

Medicaid funds began to be available to some in 1981. The Home and Community-Based Waiver (HCBW) applied to individuals who had been in state institutions and were being discharged to community services. Since many such facilities denied admission to persons with autism, their families did not even have that safety net, such as it was.

Now every state has funds for adults with DD in community-based settings. However, there is only eligibility, not entitlement. Funding from the HCBW fluctuates with economic health and is often cut or frozen. Currently, several states have long waiting lists. However, in recent years, more VR services have been made

available for individuals with DD, like mental retardation and, even more recently, autism. VR counselors with some DD background are sometimes surprised at how differently they must approach individuals with autism.

VR services—started after World War I to train and assist disabled veterans in new job skills—were never meant to be long term, but because they serve adults, VR agencies began to be contacted for post-school-aged individuals with ASD. At first, the rigid timelines for services kept most people with autism from the long-term employment support they needed. In the late 1990s the HCBW funding began to allow reimbursement for supported employment, but VR funding must first be exhausted. This helps explain the current rise in requests to VR for services for adults with autism.

Those who know autism well understand that services for this population are for *habilitation* not *re-habilitation*. They also know progress can be made—sometimes dramatic and heartwarming—even with clients who have very difficult behaviors. The process is slow, tedious, staff-intensive, and long term. Success depends on the skills of supervisory staff and managers who must be knowledgeable about autism and constantly train, monitor, supervise, and support direct care staff. In order to be effective, these hands-on staff must have a high energy level, physical stamina, intellectual curiosity, maturity with generally good mental health, a high threshold for frustration, and a commitment to excellence (Sullivan & Hayes, 1985, 1986).

We hope this manual will be useful for VR counselors and their colleagues as they increasingly meet and navigate the rough waters for adults with autism in the real world of work.

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Chapter 1

INTRODUCTION TO AUTISM SPECTRUM DISORDER

By Lee Grossman and Cathy Pratt

Autism used to be considered a relatively rare disability, occurring in approximately 1 to 2 per 10,000 individuals. Today the incidence continues to grow at an alarming rate. The Centers for Disease Control and Prevention (CDC) described the current incidence as 1 in 150 (CDC, 2007). Regardless of the exact number, the reality is that more individuals receive this diagnosis.

As autism spectrum disorder (ASD) is a lifelong condition, the costs associated with treating it are as high as \$3.2 million (Harvard School of Public Health, 2006). The high costs of treatment and interventions along with the growing numbers of individuals affected are placing enormous challenges and burdens on U.S. service providers. As a result, our human service systems and schools are stretched to understand this disability and to provide quality services. The majority of focus has been on early intervention, with the belief that early and intensive intervention can lead to better outcomes. Ultimately, the hope is that individuals will require less support as adults if early intervention is effectively done. It is too early to know if this is the case. What we do know is that just as autism is a spectrum disorder, so too are the services these individuals will need as adults. Some will be able to live in supported living arrangements; others will require more intensive support. Some will hold meaningful jobs in the community, and for others we all will have to be more creative when pursuing options.

Chapter 1

The data show that the population of people with ASD is perhaps the greatest underserved disability group in the vocational rehabilitation system. Almost all individuals with ASD have skills and talents that can be developed to allow them to maintain meaningful employment. It is the unique role of the vocational rehabilitation counselor to be able to identify these abilities and match them with the opportunities and supports necessary to achieve employment.

Much has been learned over the past decade about the treatments and interventions for people on the autism spectrum. We know that these individuals are lifelong learners who have tremendous potential and can be productive and contributing members of society.

The first step in being able to effectively program for these individuals is to understand the diagnosis. The remainder of this chapter describes ASD, including the process for diagnosing it and the potential causes related to onset.

Understanding the Diagnosis of ASD

You may have heard the word *autism* on the movie *Rain Man* or on special segments of recent TV news programs. You may have read articles in the newspaper, or you may have heard personal references to a child with autism. However, you may be less familiar with the term ASD.

Most people with the diagnosis of ASD have been diagnosed using the Diagnostic and Statistical Manual (DSM) criteria. The DSM is a manual of all the possible diagnostic categories approved by the American Psychological Association. Prior to 1994, the DSM had only two categories under the heading pervasive developmental disorders (PDD): autism and pervasive developmental disorders—not otherwise specified (PDD-NOS), or atypical autism. In 1994, when the fourth edition of DSM was published, five categories appeared under the PDD heading: autism, PDD-NOS, Asperger's syndrome, Rett's syndrome, and childhood disintegrative disorder. Rett's and childhood disintegrative disorder are both regressive neurological disorders: individuals lose skills, and that loss is permanent and progressive. The first three categories— autism,

Asperger's, and PDD-NOS—are typically referred to as ASD. Those with ASD usually continue to develop new skills. The term ASD is used to represent the fact that while these individuals share common characteristics, how these characteristics are manifested will differ with each individual. As a result, no two individuals are the same.

Diagnosing ASD is sometimes complicated because no medical test, blood test, or radiological image will quickly and definitively indicate that a person has one of the ASD diagnoses. An accurate diagnosis is based on an observation of specific behavioral characteristics across a variety of environments. The behavioral characteristics typically used are listed in the DSM.

In making the diagnosis, evaluators should consider a comprehensive history of early development, outlining family history, birth complications, and developmental milestones. Additional information should be gathered via interviews with family members or relevant caregivers and via formal and informal assessment.

While our sophistication in diagnosing ASD in children is increasing, many children continue to be undiagnosed or misdiagnosed. Sometimes this situation occurs because of differences in the experience and training of the evaluators. Other times it is due to the fact that the child has more than one disability or special challenges or has had a life event that causes people to consider an alternative diagnosis. As individuals reach adulthood, achieving an accurate diagnosis may be complicated when no one is available to describe the developmental history.

ASD can be diagnosed by a physician, a psychologist with a certain level of credentialing, or a psychiatrist. Specific tools can be used to check for ASD. These instruments include the Autism Diagnostic Interview-Revised (ADI), the Autism Diagnostic Observation Schedule (ADOS), the Gilliam Autism Rating Scale (GARS), the Asperger Syndrome Diagnostic Scale (ASDS), the Childhood Autism Rating Scale (CARS), and tests of cognitive abilities such as the Test of Nonverbal Intelligence (TONI-3), the Leiter-R, or another instrument.

Chapter 1

As mentioned earlier, getting an accurate diagnosis is more complicated when the individual has other medical, sensory, emotional, or learning difficulties or differences. Individuals may range from having a severe/profound cognitive impairment to being very gifted in general or in specific areas. When an individual is gifted in a specific area, he or she is often referred to as being a savant. These individuals may have exceptional talents in calculating numbers, playing a musical instrument, or drawing. Certain individuals have attention deficit hyperactivity disorder, mood disorders such as depression, or other mental health issues, such as bipolar disorder, clinical anxiety, or obsessive-compulsive disorder. Some have learning disabilities, seizures, Tourette's syndrome, Fragile X, or allergy problems. A few have vision or hearing impairments. A subgroup seems to have chronic gastrointestinal problems and ear infections.

The majority of individuals with ASD are male, with a ratio of 4 to 1. In some states, reported cases have jumped by more than 25% in a year. The number of people with ASD exceeds the number with Down syndrome. Our country currently has approximately 1.5 million individuals on the autism spectrum.

There is no known cause of ASD, although there are many theories about potential causes. As research continues, it appears that multiple factors are involved. Current research points to the following possibilities: viral infections, adverse reaction to childhood immunizations, pollutant exposure during pregnancy, metabolic disorders, enzyme deficiencies, birth complications, and/or various defects in body chemistry or the immune system.

At present, genetics seems to play a role, but numerous chromosomes seem to be involved. It is possible that an individual with ASD may have siblings on the autism spectrum or have other family members with the diagnosis or with characteristics of it. Immediate and extended family members also seem to have a higher incidence of sensory difficulties, depression, obsessive-compulsive disorder, and other related disorders. Regardless of its cause, we know that ASD is neurologically based and not emotionally or behaviorally based. And we know that ASD is not caused by poor parenting.

The manifestation of ASD can vary by individual. Children usually develop more skills and understanding as they age and as they have more experiences. The next section highlights some of the specific characteristics experienced by children on the autism spectrum.

Core Characteristics of ASD

In this section, we discuss three core and defining characteristics of those with the diagnosis of ASD: difficulties with social skills, difficulties with communication, and a restricted repertoire of activities and interests. We also discuss problematic behavior, sensory dysfunction, difficulties with executive function, and difficulties with “theory of mind.”

Difficulties with Social Skills

Have you ever made a mistake in social situations? Told a joke that did not fit the event? Revealed a secret? Misread the intentions of others? If you have, then it is easier for you to understand why individuals on the autism spectrum have such difficulty in social situations. Think about the demands that social situations place on us. We must be able to make quick judgments and respond sometimes to unpredictable events. We must be able to read the facial expressions and body gestures of others. We must be able to understand sarcasm and not take things literally. We must understand the ever-shifting social rules and the reality that there is much that is “gray” about social situations. For individuals with autism, these skills are missing or are functioning at a deficit. As such, social difficulties are a defining characteristic of those with ASD.

Social difficulties are the primary reason that many adults with this diagnosis are challenged in employment situations. When they are young, some have minimal interest in playing or being with other people. As children, some will not engage in reciprocal social interaction. When social engagement does occur, it is typically on their own terms or is very awkward. At the same time, these responses may reflect a lack of skill in knowing how to interact rather than a lack of desire.

Chapter 1

Even in adulthood, most still struggle to understand the social, verbal, and nonverbal behavior of others within complex social situations. Often individuals with ASD are socially naïve and easy prey for predators such as bullies. Often they have limited gestures, have awkward body language, and/or say honest or inappropriate statements to others that should have been kept private. Deficits in social interactions can also impact the ability to initiate, maintain, reciprocate, and terminate conversations with peers or adults. In addition to being literal, individuals on the autism spectrum may not be able to function or find exception outside of the concrete rules or boundaries that either they have learned or that have been established for them. As a result, many with ASD have difficulty changing or altering their routine and will need additional supports and time transitioning to new or unfamiliar experiences.

Difficulties with Communication

Communication difficulties also vary across individuals on the autism spectrum. Some can be very articulate, even as young elementary school students. Some will ask incessant questions. Often this represents a bid for interaction and attention rather than a bid for information. Some are delayed in learning to talk and use language. These children usually do not compensate by using extensive gesturing and pointing. Instead, young children may put an adult's hand on what they want, pull the adult over to the object they want to access, or engage in problematic behaviors to express their message.

When working with any individuals on the autism spectrum, it is imperative to understand the method they use to express themselves and teach them viable ways so that everyone can understand the meaning. Some individuals may grunt, point a finger, pull an adult to an area, or use a picture cue, a single word, a phrase, or a complete sentence, depending on whether they have any verbal skills. Some may never develop meaningful speech and will need to use signing and/or augmentative communication devices. Others begin their journey towards developing oral communication skills by using echolalia. Some have a very restricted repertoire of use of their communication skills and need direct instruction and support to expand their skills. Even those who develop oral skills often have other language/communication problems in social and academic situations.

If the individual does have verbal skills, he or she may often use an idiosyncratic vocabulary. For example, one person used “ear muffs” to mean headphones. Everyone working with the individual needs to help create an ongoing list of words that the individual uses in order to understand his or her language.

Individuals with ASD are very concrete in their understanding of the world and can have significant comprehension problems and significant gaps in their store of background knowledge. The person with ASD tends to interpret language in a literal manner. For example, a peer says, “I could eat a horse.” The individual with ASD will look around for a horse and wonder how the friend is going to eat a horse. Since individuals with ASD often misinterpret language, they may see jokes and sarcasm as lies and then mistrust the speakers.

Everyone processes what they hear (receptively) at different speeds. Some may be able to process information quickly. Others may hear the instruction to line up for lunch and not respond for 4 minutes. This behavior should not be interpreted as being oppositional. It is best to allow the time needed by waiting or walking away from the individual before giving another direction or setting a limit. Another option is to use visual prompts to augment verbal requests.

Individuals with ASD can have higher verbal language ability but lack reciprocal conversation ability. An individual starts telling his coworkers which fluorescent lights in the hallway are going to burn out today. He continues to explain the way the light is circuited and how an electrician works on lights. He doesn’t wait for any comments from his peer or notice how the person is reacting to his initial conversation. Actually, he believes that since he is interested in the operation of lights, everyone else is too. This individual needs to be taught how to have reciprocal conversations.

Restricted Repertoire of Activities or Interests

The other significant area that is part of DSM criteria involves repetitive, restrictive, and stereotypical behavior. This too varies by individual, by age, by circumstance, and by the level of

Chapter 1

awareness about others. Rocking one's body, for example, is a stereotypical behavior. It can occur when the individual is anxious or agitated at home, school, and in community situations. Some are taught, as they get older, that this is a behavior that they should not do in the community but can do at home.

Repetitive behaviors might include lining things up, ensuring that all cupboard doors are closed, aligning chairs in a certain fashion, and making certain noises. Stereotyped movements might include hand flapping, rocking, spinning, jumping, and other patterns.

Restrictive behavior involves having a narrow set of interests. Trains, air conditioners, mileage between cities, computers, or credits at the end of movies are some examples of favorite topics of interest. There may be no interest in talking about or doing things outside of the current topic area. Some become walking encyclopedias of facts on certain topics. Because there is comfort in routine or sameness, these individuals often have difficulty shifting from a favorite topic. On the other hand, these areas of intense interest can be used to motivate learning and as reinforcement.

Problematic Behavior

Perhaps the greatest challenge to those who interact with individuals across the autism spectrum is the presence of challenging behaviors. The individual may exhibit ritualistic or compulsive mannerisms, self-stimulatory behavior, refusal, withdrawal, self-injury/abuse, property destruction, or physical aggression.

One individual repeatedly pushed his chair into his desk every time he got up. In addition, he walked to all locations using a pattern of three steps forward and two steps back (e.g., even if he was just going to get a drink of water). This is an example of a ritualistic behavior. Others may flap their arms, brush their hands against their face repeatedly, rock, or hum as a self-stimulatory behavior. An example of refusal is an individual who does not want to enter an area or complete work. When an individual is withdrawn, it is usually because he or she prefers to be alone. Some may exhibit

self-injury by biting themselves on the hand, picking their scabs, showing no fear, or putting themselves in harmful situations (e.g., standing in front of moving cars). Other may react to their environment by physically hurting their siblings, peers, family members, or staff. The important point to remember is that outward behaviors are typically symptoms of issues in the person's life. These issues may include lack of communication skills, sensory dysfunction, illness, poor opportunities, poor home environment, or poor quality of life. Our job is to determine the underlying cause and to develop a behavior support plan to address these causes.

Sensory Dysfunction

Our senses are conditioned to organize and interact with the world around us. It is important to realize, understand, and accept that some individuals on the autism spectrum may actually feel, hear, see, smell, and taste at an extreme level. They may be hypersensitive (overreactive) or hyposensitive (underreactive). In addition, the way their body balances, moves, and is positioned in the environment affects their sensory processing abilities. Below are the various ways that sensory challenges impact these individuals.

Touch is an important sense that is needed for social interactions with loved ones or to show care for a person. However, some with ASD don't like to be touched. If they are slightly bumped in the hallway or have a tag inside of their shirt, it feels like someone is inflicting terrible pain on them. Others need deep pressure through a firm touch, tight clothes, deep massage, or by sleeping between their mattresses. Some people with ASD have a high tolerance for pain and may not realize a shoulder is broken until it is swollen for several days.

Auditory sense is difficult to block out. Some can hear bugs tapping on the window or the fluorescent lights in the room buzz. Imagine how it would feel to hear a fire alarm, vacuum cleaner, or a room full of children at a birthday party at a magnified level. Challenge yourself to be in tune with the many sounds (e.g., ticking of clock, wind blowing, grass being mowed) that are within

Chapter 1

all environments. Others will respond by acting like they can't hear a person. Many individuals with ASD also have difficulties processing auditory information. An individual may have difficulty discriminating between sounds, remembering directions, paying attention to a voice, and/or reading aloud.

Vestibular sensations occur in our inner ear. The inner ear receptors register every movement we make and every change in head position. This encompasses messages from our neck, eyes, and body. Rotary movements involve moving in circles (e.g., spinning). Linear movements (i.e., back and forth, side to side, up and down), especially when rapid (i.e., rocking in a chair, swaying, swinging on a tire), may cause most to become dizzy, nauseated, or to get a headache. Individuals with ASD may actually crave these kinds of movements. They crave linear movement, which means they need a lot of vigorous activity in order to get started. Some become distressed and show anxiety due to a fear of falling, being picked up, standing up, or sledding down a hill.

For the visual senses, individuals with ASD may be distracted by objects hanging from the ceiling, feel blinded by the sun, or be unable to focus in the presence of fluorescent lighting. Others may perseverate on shiny objects that spin or watch the reflection of light bouncing off of the walls.

Smell and taste are commonly overlooked by people working with individuals on the autism spectrum. Yet some are highly agitated by perfumes, the odor of foods or animals, hand lotions, flatulence (gas), menstruation, and certain environments (e.g., farms, restaurants, pet stores). Some may gag if a food that tastes terrible is presented. Those who are hypersensitive to smells may avoid people, places, or foods so they are not around the odor. Yet individuals who are hyposensitive to smells may crave odors or tastes. They may lick or taste inedible objects (e.g., Play-Doh, chalk) or prefer spicy, hot, or sour foods.

Proprioceptive feedback helps us position our bodies and move through the environment. Proprioceptors exist in our muscles, joints, ligaments, tendons, and connective tissue. Proprioceptors work closely with tactile and vestibular systems through body

awareness, motor control/planning, and postural stability.

Individuals with ASD may need to keep their eyes open in order to know how their own body is moving. Motor control/planning involves coordinating one's gross and fine motor skills within the environment. Those who have difficulty in this area may bump into people or obstacles or frequently fall or trip.

Some cannot regulate how much pressure to exert when grasping an object. As a result they hold pencils too tightly, and their written work is messy. Finally, individuals on the autism spectrum may have poor posture, lean their head on their hands, and be unable to balance on one foot. In all of these areas, individuals may feel emotionally insecure due to feeling uncomfortable or inadequate, rigid, or intimidated by the environment.

It is imperative to accommodate individuals with sensory needs throughout the day to help them calm their nervous systems so they can function in home, community, or work. These breaks should not be considered a reward but as a necessary requirement for a person's day.

Difficulties with Executive Function

Individuals on the autism spectrum have a difficult time organizing and handling multiple tasks. They are better at performing one activity at a time. As a result, they will have a hard time multitasking, completing assignments that require multiple tasks, showing up to work with all the materials needed, or performing a job that requires multiple job duties. Executive functions also include deficits in the area of making transitions and organizing oneself.

Difficulties with "Theory of Mind"

Individuals on the autism spectrum have difficulty with theory of mind. In other words, they have difficulty inferring other people's mental states (e.g., thoughts, beliefs, desires, intentions). As a result, some individuals are taken advantage of because they cannot read the true intentions of others. Individuals on the autism spectrum also have difficulty differentiating fact from fiction. In extreme cases, individuals have begun to believe that they are a

Chapter 1

specific cartoon character or an animal (e.g., cat, dog). This quality may also result in them developing unrealistic long-term goals, such as believing that they can become a Hollywood director simply by showing up in California.

Other Challenges

In addition to these characteristics, individuals on the autism spectrum may have difficulty with toilet training, may be extremely picky eaters, may develop seizures, may not sleep well throughout the night, and may have other health issues (e.g., chronic early infections, gastrointestinal difficulties).

Conclusion

Autism is a complex neurobiological disorder. Although the ADS population has unique challenges, their potential is unlimited, and much can be done to help and improve their lives. It is through knowledge and understanding of the condition that we will continue to show progress and provide greater opportunities to those on the autism spectrum.

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Chapter 2

TRANSITION PLANNING FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS

By David Larson Holmes and Katy Chaffee

This chapter introduces the essential elements of successful transition planning for students with autism spectrum disorder (ASD) and sensitizes the vocational rehabilitation (VR) counselor to the needs of these young adults and their families.

It is generally accepted that an education for all children in the U.S. is designed to maximize their capacities in adult life. For adolescents with ASD, planning for adulthood is all the more critical (Gerhardt & Holmes, 2005; Moore, 1994; Rusch, Destefano, Chadsey-Rusch, Phelps, & Szymanski, 1992).

The July 2004 reauthorization of the Individuals with Disabilities Education Improvement Act (IDEA) recommended moving transition planning to age 16, rather than 14 years as established in prior reauthorizations (IDEA, 2004). Although states have the authority to establish the age for each special needs student's transition individualized education plan (IEP), the law is clear, in Sec. 614(d)(1)(A)(VIII), that such IEPs are to be established no later than the student's 16th birthday (IDEA, 2004; Will, 1984; Snauwaert, 1992).

Families and professionals who work with individuals on the autism spectrum recognize that a transitional IEP will be as varied

Chapter 2

as there are unique learning needs for these adolescents (Wehman, 1992; Berkell, 1992). As such, for some youth, transition planning will occur unofficially during the child's earlier educational years, whereas for others, transition planning will occur officially at age 16 (Interagency Autism Coordinating Council [IACC], 2005).

America has one of the best public education systems in the world. It promises to prepare its children to be able to live the American dream. Yet, for people with ASD, that promise is rarely realized.

After years of struggling through their education years, often through their 21st birthday, adults with autism find themselves with limited opportunity to enjoy gainful employment and to live and recreate to their capacity in the communities in which they live (Holmes & Shore, 2005).

Story: Mary

Mary's story is one such illustration. After graduating from a specialized autism program at age 21, no appropriate program of services was available for her. She returned home to live with her mother, who returned each night drained from work. Meanwhile, Mary no longer had a reason to get up in the morning and would lie in bed until noon. Before long, her self-injurious behavior returned and she became depressed, sitting passively in the dark. Mary was a different person during her school years when she had staffing, structured activities, and peers her own age. Now, her mother said, "I feel as if we've been derailed and can't get back on track."

It has been recently noted that if adults with autism do not transition into employment after their education years, they have a 70% chance of not being gainfully employed throughout their lives (Roebuck, 2006). Or, if one wants to view the data optimistically, they have a 30% chance of gaining employment.

The service needs of adults with ASD, as mentioned earlier, are as varied as there are people on the spectrum (Levy, 1983). It has been said that people with ASD are like *snowflakes*—each looking similar from afar yet presenting a unique profile up close.

Differences aside, services for all adults with ASD have two attributes: structure and consistency, both of which result in *predictability*. Such service attributes are a prosthesis for those with ASD.

A prosthetic environment for those with ASD is an accommodation or assistive technique not unlike a wheelchair for those with physical disabilities (Holmes, 1998). For example, having a clearly circumscribed visual schedule for the person to follow throughout the day will help to take the “guess work” out of what’s next. Such a schedule will reduce anxiety and enable greater degrees of independence and productivity for the adult with ASD.

Story: Michael

Michael’s situation demonstrates the critical effect of the prosthetic environment for quality of life. Michael is a relatively high functioning young adult with ASD who has an IQ of 60. Because he was very aggressive, he was consigned to an institutional life of eating, getting locked up, and sleeping. When he finally transferred into a group home, he had no idea how to occupy himself appropriately, had poor communication skills, and had no ability to make choices. He hoarded food and ate very fast. After receiving proper training and clearly defined expectations, presented in a consistent and highly structured fashion, Michael is now able to work during the day and successfully live in his group home. Both settings have similar expectations for Michael’s behavior and have visual schedules of activities and jobs so that he can have a day of predictability. Under such conditions he is productive, happier, and less anxious—although he still worries about being sent back to the institution “if I am bad.”

Prosthetic environments fall into many categories, such as postsecondary education, employment, living arrangements, recreational/leisure opportunities, physical capacities, spiritual health, nutritional balance, and medical and behavioral health care, just to name a few. These key areas of transition planning are discussed in the next section.

Key Areas of Transition Planning

Postsecondary Education and Training

With the passage of the Rehabilitation Act of 1973 and Americans with Disabilities Act of 1990, the numbers of students with ASD attending postsecondary educational services has increased (Thomas, 2000).

Individuals with ASD benefit from postsecondary education and training options tailored to life interests and career goals. Careful consideration and arrangement of necessary supports and accommodation often make the difference in the success of the experience. Weir (2004) explained that no matter the capacity of the individual attending postsecondary education activities, some key elements need to be addressed: interagency collaborations for supporting success, innovative use of funding resources, preplanning (transition planning) focusing on the individual's life goals, and a willingness to expect that the individual will learn and succeed by all parties who are responsible. Appendix A, "Planning for Postsecondary Education and Training," references useful resources and websites and highlights the importance of internships and other work experiences.

Employment

Since adults with ASD vary widely in their skills and abilities as well as functional needs, employment involves an equally wide range of opportunities, from secure/sheltered settings to supported employment and competitive employment (Holmes, 1998).

Given both the significance of work and the inherent difficulties for those with ASD to successfully navigate the requirements for employment, schools and posteducation agencies should focus on this critical goal of employment.

Appendix B includes a form for summarizing employment-related information for students as they first transition to employment. Although the form was designed for students with severe disabilities and communication issues, it will be instructive for those less affected by autism as well.

Finally, as with postsecondary education opportunities, employment for adults with ASD typically will require accommodations and accessibility as outlined in the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990.

Living Arrangements

Adults with ASD may use a variety of living options to satisfy their unique lifestyle needs. Such arrangements can include supported living conditions in their family home, a group home, a supervised apartment, or in their own home or apartment. Supports under various living arrangements can be as intense as “line-of-sight” supervision or as minimal as a phone call or semimonthly visit to inquire how the person is doing.

Recreation/Leisure Opportunities

Equally important is the consideration of access to recreation/leisure activities in order to maintain physical and social well-being. The creative use of unstructured time is challenging for many young adults, especially when complicated by transportation, funding, or other necessary arrangements. For some individuals, the solution may be as simple as assisting with organizing or scheduling activities.

Physical Capacities

Adults with ASD benefit from a plan for aerobic and resistance training to ensure physical capacities: cardiovascular health, muscle strength, weight control, mental alertness, and endurance. Additionally, regular exercise contributes to the reduction of stress and anxiety, affecting behavior and job performance.

Spiritual Health

A holistic transition plan asks consumers with ASD and their families to consider the enhancement of their spiritual life and direction. For many young adults with ASD, spiritually focused activities are important and a shared part of family life.

Chapter 2

Nutritional Balance

Diet plays a major role in health and daily performance. As the awareness of the effects of food and nutrients on the behavior and well-being of people grows, so does sensitivity to such matters for individuals with ASD.

Medical and Behavioral Health Care

The majority of people with autism receive inadequate medical and behavioral health care when they do not have the verbal or cognitive capacity to describe medical or psychological symptoms. People on the autism spectrum often require services by professionals who are well trained in observational diagnoses, as well as in utilizing family history interviews and/or interviews with significant caregivers. Essential behavioral health services range from one-to-one behavioral supports for some to merely having access to a social worker when encountering stressful events for others. Medical health needs can be as intense as requiring full anesthesia for dental work to the less intense need to have a scheduled annual examination (Holmes & Shore, 2005).

A Final Consideration: Behavioral Issues

Whether consumers with ASD are planning to pursue postsecondary education or work, a different living arrangement or the same one, it is important to understand their behavior in context. Their behavior is motivated by the same factors that drive all of us: the need to feel in control, to not be isolated, to feel safe, to be understood, and to have basic biological needs met.

Ellen Notbohm, in her book *Ten Things Your Student with Autism Wishes You Knew* (2005), reviewed the issues that she perceives are critical in understanding the behavior of children with ASD (see Appendix C). She explained that the behavior of individuals with ASD is a form of communication. “Problem behaviors,” for example, can be a signal that an individual with ASD is experiencing distress from sensory sensitivities. To prevent such problem behavior, adults need to allow breaks for self-regulation, offer choices, facilitate transitions, and deal with difficult behaviors through supportive problem-solving when the child is no longer upset and emotionally unavailable.

The “Ten Things” are also applicable to adults with ASD. VR counselors must keep these issues in mind if they are to be successful in understanding the needs of individuals with ASD and in finding the proper service matches for them.

The Process of Transition Planning

For all individuals with ASD, a written transition plan must be established with input from the persons with ASD, their families, professionals, and responsible agencies. Transition planning must actively involve the individual with ASD in a way that is tailored and most appropriate for that individual. For example, planning sessions that involve lots of people are often not the most fruitful or productive format to best engage the thinking of young adults with ASD who may benefit from explanations and more time for processing information.

When considering the transition IEP, it is critical that the VR counselor be a member of the transition team, as outlined in IDEA. The VR counselor must challenge the team to consider employability skill development during the student’s final educational years. Such skills include attention to tasks with reduced supervision; completion of tasks with both quantity and quality measures; social skill development; capacity building in small group instruction; capacity building to wait one’s turn and respect personal space; and proper grooming, personal hygiene, and appropriate attire.

Better Early Than Late

It is best to begin transition planning for the adult world earlier rather than later for those more severely afflicted on the autism spectrum (Holmes, 2005). As early as the elementary years, one should ask the question, “Will this activity be necessary for success in the student’s adult life?” If not, a focus on activities of daily living must be of the highest priority. All other pedagogical activities take a second place until the child demonstrates responsible behavior in the areas of safety, personal grooming, personal hygiene, respect for others, and respect for personal property. For all others on the spectrum, a transition plan, either at 14 or 16 years of age, may be adequate (Holmes, 2005).

Chapter 2

A transition plan needs to state current levels of ability and current life skill needs; identify the necessary accommodations and supports required for success; describe the types of training necessary for the professionals who will be serving the individual going forward; and describe the transition process in detail, with timelines (Steere, Wood, Pancsofar, & Rucker, 1993). Such timelines must be operationally defined with goals and objectives, functional in nature, and based upon the student's capacities.

Transition planning provides the student and his or her family with the opportunity to visit a variety of settings that will meet the student's needs in adulthood. It should also be sensitive to the expected dynamic development of the student and ensure that the student continues to be challenged during the transition period with the understanding that "the issue today is less than one of access. . . . The question is making sure that students with special needs have access to a challenging educational program" (National Association of State Directors of Special Education, 2006).

Follow Through

A transition plan must include a process for ensuring success of the plan over time by responsible personnel. The transition plan summary (see Figure) can serve as a guide in developing appropriate transition plans (Department of Health and Senior Services, 2003; Gerhardt & Holmes, 2005; Wehman, Kregel, & Barcus, 1985).

Legal Issues

As noted in the Figure, two areas that need attention in transition planning for students with ASD are guardianship and financial planning. Without proper financial planning, children/youth with autism, upon becoming adults, may be ineligible for Medicaid supports and Supplemental Security Income (Block, 2005).

Special needs trusts are important means for many to secure federal support for adult services. Currently, the amount that an individual with a disability can have and remain eligible for federal support in adulthood is \$2,000.00. While some may find relying on federal subsidy distasteful, they should consider that residential

supports and employment supports can run into the hundreds of thousands of dollars for adults with autism (Hinkle, 2004).

Establishing guardianship should be a thoughtful process, as it may involve removing or restricting rights of the individual. Less-restrictive options than full guardianship should be explored to determine if any of these options meet the individual's needs. Examples of some alternatives to guardianship include

- Representative payee
- Case management
- Health care surrogacy
- Power of attorney
- Joint checking account

The National Guardianship Association has good information on guardianship issues and options on its website:
<http://www.guardianship.org>.

Guardianship laws vary from state to state. If a parent or other adult doesn't obtain guardianship for their child or youth with autism, at the age of majority that person automatically becomes an independent adult. Guardianship may be necessary for most adults with autism, especially those who have more severe cognitive impairment.

An alternative to guardianship is a durable power of attorney, and such a document works well for high-functioning individuals who may need help making medical or other life-affirming decisions (Block, 2005; Kaplin & Moore, 1989).

Model Transition Plan

Date: _____

DIRECTIONS: To be completed by parent/guardian with support from staff who are assisting the family with the transition process. Any transition planning must actively involve the individual with ASD in a way that is tailored and most appropriate for that individual. This summary should be completed prior to the transition planning conference held when the child reaches 16 years of age. Information summarized is intended to help begin the conversation during the transition planning conference.

Name of Student _____

Date of Birth _____

Parent/Guardian _____

Telephone Number _____

Street Address _____

City _____ State _____ Zip Code _____

E-Mail Address _____

School District _____

Case Manager _____

Telephone Number _____

Vocational Counselor _____

Telephone Number _____

Current Program _____

Contact Person _____

Telephone Number _____

Service Coordinator _____

Telephone Number _____

Figure. A sample transition plan. (Continued on next two pages.)

GENERAL INFORMATION – Please summarize below:

1. Significant birth history:
2. Diagnosis or presenting issues:
3. Medical or neurological information:
4. Special or health-related information, including medications list:
5. Crisis issues and interventions:
6. The student's program and progress, with a focus on strategies that have been most successful (e.g., current services, adaptations, accommodations, training of support personnel and professionals, etc.):
7. Family's priorities approaching transition to adulthood:
8. Expectations for postsecondary education and training:
9. Expectations for employment (e.g., vocational evaluation, assistive technology, job coach, supported employment, job placement, etc.):
10. Expectations for living arrangements:
11. Expectations for recreational/leisure activities:
12. Expectations for behavioral health/health care:
13. Expectations for transportation:

Chapter 2

14. Expectations for social skill enhancement:
15. Expectations for social support groups (e.g., family, friends, groups, etc.):
16. Expectations for communication skill development:
17. Expectations for sexual expression:
18. Personal hygiene and grooming:
19. Nutritional requirements:
20. Physical/cardiovascular expectations:
21. Spiritual life expectations:
22. Guardianship:
23. Financial planning:
24. Health and life benefits (e.g., living wills, health insurance, life insurance, funeral expenses, etc.):
25. Service agency profile (e.g., the types of services or agencies required to offer such services):

Prepared by: _____

Date: _____

Parents/Guardians: _____

Date: _____

Summary

In preparing a transition plan for students with autism, it is critical that everyone responsible for the plan be involved in the process, including those authorized to offer postsecondary educational services, such as VR as well as developmental disabilities agencies. Families are critical members of the transition team along with individuals with ASD as appropriate (Hosack & Malkums, 1992; Irvin, Thorin, & Singer, 1993).

The plan should be all-inclusive, addressing a compendium of domains: current levels of behavior, postsecondary education and employment, living arrangements, recreational/ leisure/physical activities, nutrition/behavioral health/health care needs, transportation, social skill enhancement, communication, sexual expression, spiritual concerns, and, finally, financial planning, guardianship, and other legal matters (Holmes, 2005). Unfortunately, all of the best-designed transition plans frequently lay fallow, as there are inadequate adult supports for individuals with ASD (Holmes, 1999).

The Role of the VR Counselor in Securing Appropriate Services and Assisting Families and Individuals During and After the Transition Process

Family is essential to the transition process for any student, and those diagnosed with ASD are no exception. “Family” is defined in the broad sense as those who have been committed, involved carers or caregivers with an intimate knowledge of the young adult consumer. Parents and family are often the most helpful historians, providing the VR counselor with an essential level of detail about the background, experiences, and functional needs of the consumer. For example, specifics about playtime preferences may give hints for future career directions.

Receiving Input from the Family

Family input early in the VR process establishes a solid foundation for planning and builds a critical counselor-family connection at the same time. From the first meeting, the VR counselor needs to establish trustworthy relationships that respect and include both the

Chapter 2

young adult and the family. Parents and young adults each bring their own anxieties to initial meetings with adult service agencies such as VR. In some cases, students with ASD may be sensitive to having others represent them, especially in relation to disabilities. Like their same-age peers, they want to be seen as capable and want to exercise some control over their own lives, especially at intake. On the other hand, some parents are prepared to talk nonstop, bringing folders thick with evaluations and other information. Others do not feel comfortable with yet another new person or agency becoming involved in their lives. One parent described her experience of transition as “being asked to live in a glass fishbowl again. I did that for so many years, and I don’t want to do it anymore.”

Characteristically, a child on the autism spectrum and his or her parents have a long history of working with multiple professionals such as psychologists, physical therapists, occupational therapists, speech and language pathologists, autism consultants, physicians, case managers, developmental services providers, counselors, and classroom teachers. As a result of their intimate level of involvement and commitment, parents are in the position of “having greater expertise than many of the professionals working with their child, many of whom may have not had experience with autism” (Marcus, Kunce, & Schopler, 2005). Parents of young adults with ASD have well-earned concerns about both the training of professionals and the quality of services available to meet the needs of those dealing with ASD.

Appropriate questions demonstrate the counselor’s appreciation for the highly unique and diverse effects of autism for any given individual—as well as provide invaluable information. Some sample questions are as follows:

- What are the student’s area(s) of special interest and skill? Thoughts of career direction?
- What training might be useful for her/his career direction?
- What kind of employment experiences has she/he had, and what did she/he like the best? What accommodations or assistance make work go well?
- What does the student find rewarding?

Transition Planning for Individuals with ASD

- Are there significant sleep issues? Problem behaviors? Special sensitivities?
- What helps the student cope or release tension?
- What is the student's level of independence—with daily hygiene, schedules and time, safety, following directions, handling money, and engagement in the community?

Focusing on the Student's Passions

The VR counselor needs to show respect for a student's "passions" and explore those passions with the student. Often a person with ASD will develop an area of strong interest that to others seems unusual in either the topic or intensity. Reframing these areas of interest from "obsessions" or "narrow fields of interest" into "passions" can be an effective way to develop and enhance the counseling relationship. A passion is not a repetitive, obsessive-compulsive-type behavior such as flicking a light switch off and on. Rather, a passion is an activity or interest that is deeply meaningful to someone and in which they invest a lot of their time and energy.

We all have passions. We engage in these interests and activities to facilitate communication, develop relationships with others, and relax, and we engage in them because we enjoy them. In addition, those with ASD may utilize their passions to show their intelligence (many with ASD have carried labels suggesting that they have extreme difficulty learning or aren't as smart as most) and to provide order and consistency in their life (something very, very important to individuals with ASD).

In the counseling relationship, when the counselor demonstrates a genuine interest in understanding a person's passion, it opens the door for communication and relationship building. In vocational counseling, exploring a person's passion can lead to good vocational exploration and possible discovery of other passions.

Story: Dan

Dan is a young man who is passionate about the weather. During one meeting, he asked his VR counselor if he knew

Chapter 2

what a “dust devil” was. The VR counselor was savvy enough to know that Dan was not talking about vacuum cleaners but rather a meteorological event and relayed a story about a dust devil he had seen while hiking in Utah. The counselor developed a connection with Dan and was able to evoke energy for exploring possible vocational opportunities revolving around his interests.

When exploring passions, we must use caution to not misinterpret the meaning of that passion to the individual (Stillman, 2003).

Story: Jim

Jim is a young man with ASD who is very interested in guns. After incidents such as Columbine, his teachers and parents were very concerned. The VR counselor explored Jim’s passion about guns with him and discovered that Jim was not interested in guns because of the power they represented or the destruction they cause. Rather, Jim was fascinated with the mechanics and operations of the firearm. If Jim were exposed to other similar types of objects and how they worked, perhaps his passion could be expanded and developed further. It’s possible that Jim may develop into a fine engineer!

Understanding Family Stress

The VR counselor needs to be aware of the stress the family is experiencing and offer appropriate resources and information to support the family system. During their child’s adolescence, parents are often anxious about their child’s independence, responsibility, and future success. Parents of adolescents with ASD report stress levels beyond even the high levels of depression and anxiety identified by parents of children with severe intellectual disabilities (White & Hastings, 2004). Stress equates with feeling less competent and capable as parents (Lessenberry & Rehfeldt, 2004), and that feeling affects the quality of the transition experience.

Transition stressors can complicate communication and interfere with effective partnering. Acknowledging this need, the Indiana

Resource Center website offers helpful hints for maintaining “effective, consistent, and honest communication” in an article called “Setting the Stage for Parent-Professional Collaboration” (<http://www.iidc.indiana.edu/irca/family/settingstg.html>).

To safeguard the welfare of the family support system, the VR counselor may need to help the family cope with key stressors by helping them develop resources and strategies. Such strategies include referrals to parent support groups, educational resources, informational websites, access to respite care, personal counseling, and other state services such as welfare or employment help.

Understanding the Family’s Communication and Mental Health Needs

The VR counselor needs to make an effort to understand the communication and mental health needs of families of young adults with ASD. Families with an adolescent having a diagnosis of ASD may also be coping with autistic-like characteristics in other family members, including themselves. Close relatives of individuals on the spectrum are often described as more solitary, with deficits in social communication, difficulties dealing with change, desire for sameness, and mild deficits of executive functioning. A 2005 study of family histories of adolescents with ASD also showed a connection to familial histories including depression, anxiety, bipolar disorder, and schizophrenia. Recent results suggest that Asperger’s syndrome may be “more strongly genetic than autism” (Ghaziuddin, 2005).

On the other hand, transition is often emotional and complicated for many parents and teens. It is a mistake for professionals to make diagnostic assumptions about “natural and justifiable parental and sibling concerns, anger, or confusion” (Marcus et al., 2005).

Providing a Reality Check for Families

The VR counselor needs to provide the reality check for families dealing with the transition process. Parents of children with diagnoses of ASD have often spent years advocating for services and programming, as well as experiencing delight and hope in their

Chapter 2

child's accomplishments. When parents are suddenly confronting issues such as guardianship, Social Security applications, developmental disability services, and personal assistance, it can seem like conceding defeat, giving up on their dreams for their child's future. In fact, the road map for young adulthood is famous for its unknowns, its ups and downs. Children often do eventually flourish but not always within the time frame or in the ways their parents expect.

The VR counselor has practical information about services and funding that is especially valuable to the decision-making process. These systems have unique rules and processes and are not always easily understood by individuals or families. However, even when the counselor is a skilled communicator, either the parents or young adult may refuse the counselor's recommendations. In the end, the counselor must respect the choices the young adult and the family make.

Story: Jennifer

Jennifer, a young woman with artistic and design talent, was described by her vocational teacher as brilliant. However, she couldn't produce on schedule or stick with a plan. The VR counselor helped the student and family plan, with referrals to services and funding. While the young woman qualified for developmental services and was going to be provided with employment assistance to develop her talents further, she did not follow through with plans to utilize the support. Later, her parents felt badly about their daughter's loss of services, but they did not regret encouraging her independence.

Transition is a developmental process, with many steps along the way. During this time, the VR counselor works to identify the functional needs of the young adult so as to make the most appropriate match for employment. The counselor helps the young adult take the best next step while holding on to a longer-term vision of growth. Young adults with ASD, with access to essential services and appropriate training, characteristically continue to mature and develop new skills.

Recognizing Parents' Feelings of Grief and Loss

Transition can revive issues of grief and loss for parents. VR counselors need to respond with empathy and validate this experience. “With the diagnosis of autism comes the death of many dreams. This death involves the loss of family normalcy. Loss of control. Loss of hope. And intense fear. This is a lifelong process for parents who will never see their children grow up, reach developmental milestones, and live independently. . . . Because I grieve does not mean that I don’t celebrate my child” (McCullough, 2003).

Stage theories have not been the best descriptors of the experience of grief and loss for parents of children with disabilities because the sorrow does not go away, nor are the issues resolved. The mourning is different because it is by nature chronic and periodic. Parents talk about strong bonds with other parents who understand the sorrow of “the vulnerability, the loss of innocence, the recognition of our inability to control our lives or to protect our children” (Davis, 1987).

When these emotions are not recognized, they can stall or interfere with the transition planning process. Many parents have played a heroic and all-consuming role in their young adult’s life. Often hidden beneath the regimen of caregiving required by their children, emotions may not be addressed but have not vanished.

Story: Sheila

Sheila, the mother of a nonverbal autistic daughter with chronic medical conditions and recurrent behavioral problems, had difficulty with transition planning until her grief and loss were acknowledged. “I enjoy my daughter as a person and wouldn’t change her for the world. But then sometimes I just want to weep because she will never go to graduation, or college, or marry and give me grandchildren.”

At transition, the parent and the child both face a major shift in lifestyle. The parents who have been on duty day and night, 24/7, for two decades have shaped their lives and identities around a

Chapter 2

child who is now “moving on.” In some cases, a parent, most often a mother, gives up other interests to focus on responding to the intensive needs of her child (Marcus et al., 2005). The depth of required change does not happen overnight, and the VR counselor will serve as a “midwife” to an evolving process of helping the parents redefine their roles.

Helping Families Plan for Change

The VR counselor needs to help families plan for changes in roles and responsibilities that often accompany the student’s transition to adult life. As the student with ASD approaches late adolescence, new realities call for changes in the parents’ roles. First, there is a need for increased family support for employment and the development of job-related skills instead of academics. In addition, families can find that behavior management is harder with an older and larger son or daughter who has aggressive or difficult behaviors. In families, the easiest way to deal with challenging behaviors that can escalate during adolescence may be to give up and/or give in. While this approach appears to resolve the immediate situation, it does not teach the young adult to take care of himself or herself as much as possible. It is not unusual for families to experience episodes of burnout, whether from the exhaustion of dealing with odd sleep schedules or the constancy and degree of demands. Parents, like their child, are aging and do not necessarily have the same level of energy available.

At transition, there are really two important transition plans: one for the student and one for the parents. The young adult with ASD needs the parent as much as ever, if not more, as he or she takes on new responsibilities. In the meantime, parents sometimes struggle with entertaining new directions for their child’s care. For example, this may be the first time parents give serious consideration to placement outside the home. “The professional needs to be sensitive to the emotional pain experienced by parents in these circumstances” (Marcus et al., 2005). The VR counselor helps parents and families by providing access to timely information about services and support as well as assisting with problem solving and planning.

Transition Planning for Individuals with ASD

The VR counselor understands that consumers with ASD will have lifelong needs for support from their family as well as from appropriate services. Despite earlier diagnosis and improved interventions over the past 3 decades, the majority of adults with ASD remain very dependent on parents or others for support. Outcomes vary widely, even for those with higher IQ levels. Very few are fully self-supporting, and the majority are either unemployed or underemployed. Fifty-seven percent have poor or very poor employment outcomes. A “substantial minority, although continuing to be affected by their autism, can find work, may live independently, and develop meaningful relationships with others. However, the ability to function adequately in adulthood life may depend as much on the degree of support offered (by families, employment and social services) as on basic intelligence” (Howlin, Goode, Hutton, & Rutter, 2004).

Advocating for the Needs of Individuals with ASD

In closing, the VR counselor needs to help both consumers and families by advocating for the needs of individuals with ASD. This effort involves a commitment to caring about the long-term welfare of this currently vulnerable and growing population through a variety of activities:

- Developing community awareness and understanding
- Educating employers to improve work opportunities
- Staying up-to-date on new developments in the field of autism
- Supporting increased funding for appropriate, tailored services for adults with ASD, especially increased opportunities for supported living and employment

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APPENDIX A

PLANNING FOR POSTSECONDARY EDUCATION AND TRAINING

The growth in numbers of primary and secondary students with autism spectrum disorders (ASD) and the advent of earlier appropriate services to them through the individualized education program (IEP) process have resulted in increased interest in postsecondary enrollment by students with ASD. Postsecondary training and education are recognized assets for acquiring job qualifications that support career development over a lifetime. Increasing numbers of students across all disabilities are entering college: up from 2.6% of all freshmen in 1979 to 9% in 1998 (Thomas, 2000). The Rehabilitation Act of 1973 and the American With Disabilities Act in 1990 supported this increase by requiring nondiscriminatory access for qualified students with disabilities. This has created a demand for a range of disability supports. However, student support services at the postsecondary level are still in their infancy in their ability to offer the type of tailored services that may be essential for students with ASD.

Students with Asperger's syndrome are most often encouraged to consider college because their performance in high school has provided them with the academic prerequisites. But too often, students with ASD (and especially those who may have been in nonacademic high school programs) do not consider further training and education as part of their life plan. A college course, adult education offering, or other adult vocational program helps develop talents and interests that later may contribute to vocational success, as long as the student is provided with individualized structured supports.

Regardless of level of disability, students on the autism spectrum benefit from a person-centered, collaborative approach. Some key elements include interagency collaborations, innovative use of funding resources, preplanning focused on the person's goals, and willingness to take a chance on the ability of people with significant disabilities to learn and to succeed (Weir, 2004).

Exploring Postsecondary Education and Training

The school IEP/transition team assists the student and family by planning for the accommodations that will be crucial to success with postsecondary education and training. Ideally, vocational rehabilitation (VR) is involved. When this discussion happens as a prelude to visitations of programs or colleges, students and families are prepared to ask important questions of both admissions and student services/disabilities offices. The student's team addresses all aspects of the student's life—social life, daily living, and academic needs. The result of these conversations is the design of the essential safety net.

The effectiveness of the planning is enhanced when the student is prepared to participate and understands the goal. At worst, the student, without the help of a context, can perceive the discussion as a negative assessment of his or her abilities and choices. This results in discouragement and emotional upset. Some students find it difficult to understand why they need supports and may reject the team's suggestions.

Transition from high school is known to be a stressful time for families and may be even more demanding when the student is on the autism spectrum. For example, students with significant executive function issues, such as organizing, time management, and problem solving, face additional challenges in the college selection and application process. Parents find it easier to assume the responsibilities, but this is not necessarily helpful. The student's participation every step of the way is part of the process of preparing for further education. However, this is not a time for parents to step back either.

Students on the autism spectrum who are thinking about postsecondary education or training need to have a relationship with their high school guidance counselor. While it may seem like stating the obvious, students on the spectrum sometimes miss this step. Students who have a more active or comfortable relationship with their case manager or a paraprofessional can ask for help with initiating and scheduling an appointment with the guidance office. They play a primary role in helping students with funding,

Chapter 2

recommending scholarships, and reminding them of deadlines. They also handle communications required from the high school such as transcripts, recommendations, etc. By student request, the guidance counselor and/or case manager can make recommendations about accommodations to the college or program, sometimes written as a 504 plan.

The VR counselor can be most helpful when she or he gets to know the student and family in the early years of high school and gradually becomes more involved, especially as part of the college search process. The VR counselor needs to obtain a wide range of documentation from the high school, including a copy of all evaluations, the current IEP, and the high school transcript. It is useful for the VR counselor to be part of the accommodation determinations and to have a final copy of the recommendations.

Prior to graduation, the VR counselor, the student, and family meet to develop a detailed plan, including all the services and supports needed by the student. This document is called the individualized plan for employment (IPE) and is the written summary of a collaborative plan to serve as a master plan for moving forward.

As the student considers possible career directions, the VR counselor can provide expected income estimates that match potential careers. This is especially important in thinking about the long-term ability of the student to pay off college debt. The College Board website (<http://www.collegeboard.com/student/pay/loan-center/index.html>) has a “Pay for College” section that responds to the question: How much debt is too much? Today, the high costs of college generally mean that most students will have some debt, most often in the form of education loans that are later paid off in installments over a period of years. “Undergraduate student loan debt has increased significantly since 1997. The average undergraduate debt is \$18,900, up 66% from \$11,400” (Baum & O’Malley, 2003).

Self-Advocacy, Disclosure, and Success

Success requires the student to understand his or her own needs and to be able to communicate them to others. This critical issue is

too often overlooked. Students on the autism spectrum are like other students with disabilities in that they lack knowledge of their disability and its effects on their learning and living. A study of students in a disability intervention program at Boston University revealed that only half remembered being on an IEP and then did not necessarily remember its services or purpose (Clark & Lillie, 2000).

The IEP transition team needs to give careful and individualized consideration to postsecondary education preparation for the student on the autism spectrum—not only in academics, but also for social life and skills, self-regulation, daily living skills, organization, communication, and support. For example, preparatory experiences may include taking a college-level course at a community college during high school; living on campus for a summer program as a try-out; or having overnight experiences on their own, away from family, by attending conferences or camps.

A very bright, talented young woman with Asperger's syndrome arrived at college and left after only a couple of days. She had never been away from home overnight.

Disclosure and the timing of disclosure are very personal decisions and a part of self-advocacy. This is even more complicated for students who learn of their diagnosis in high school or later. Stephen Shore (2004) edited an entire book devoted to this topic called *Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum* with authors Ruth Elaine Joyner Hane, Kassiane Sibley, Stephen M. Shore, Roger Meyer, Phil Schwarz, and Liane Holliday Willey. A workbook on disability disclosure, *The 411 on Disability Disclosure: A Workbook for Youth with Disabilities*, is offered jointly by the Office of Disability Employment Policy and the National Collaborative on Workforce and Disability. The document can be purchased or downloaded at <http://www.transcen.org/>.

The New England Asperger's Association suggests that “early disclosure to appropriate college personnel improves the chances for success, and minimizes the chances of misunderstandings or

Chapter 2

unfortunate incidents. . . . We highly recommend that you give the college information about yourself and about AS after you are admitted and before the first semester” (Jekel & Loo, 2003).

The VR counselor can assist the student and family with developing a list of questions to ask colleges or schools. Investigating the ability of the college to provide services and support that match the student’s needs is crucial. The list should include pertinent questions about the social life and accommodations as well as academic considerations. The organizational and social aspects of college are recognized as more challenging than the academic demands (Shea & Mesibov, 2005). College life requires a massive amount of change and personal responsibility, not easy for any freshman. Some students have found it easier to begin their academic career at a community college and continue living at home. Online courses offer another option (Willey, 2003).

The website of the Indiana Resource Center for Autism has articles to assist with planning, such as “The Road to Post-secondary Education: Questions to Consider” by Marci Wheeler and Nancy Kalina found at <http://www.iidc.indiana.edu/irca/education/questions.html>. Williams and Palmer offer ideas in “Preparing for College: Tips for Students with HFA/Asperger’s Syndrome,” available at <http://www.teacch.com/college.html>.

Generally, each college or training program has its own website that gives the contact person and process to follow for arranging accommodations. College visits that include meeting with representatives from the student support services office are an essential ingredient to finding the right match. When the school is unfamiliar with autism and/or Asperger’s, it is helpful to provide a basic information packet to the contact for student services. In some cases the VR counselor may make calls to the college, but the family and student may also do this.

Many colleges now have some experience serving students on the autism spectrum, but few offer tailored assistance. Here is a sample of some useful college supports worth consideration:

Transition Planning for Individuals with ASD

- Access to assistive technology, especially in relation to learning needs and or planning, organization, and scheduling
- A reduced course load, at least for the first semester
- A “single” dorm room
- A social mentor
- An assigned point person to serve as liaison with the student
- Support for executive functioning needs, such as regular check-ins or help with prioritizing
- Counseling, especially related to social issues that can be quite baffling since there are many new situations, including dating, drinking, and parties

Once the college makes a determination about the accommodations, the student needs to know how to activate and use them. For example, some colleges require the student to negotiate the use of accommodations with each professor. In this case, the student is in charge of disclosure and makes use of the accommodations as necessary. One college student with Asperger’s syndrome decided on a very proactive approach: “I was really worried about dealing with professors who might not know anything about AS. I wrote a letter explaining about AS and my needs that I gave to professors at the beginning of each semester. In most cases, I think it helped create better understanding.”

The Social Experience of College

The college environment can be advantageous for the person with ASD. Campuses tend to be socially more diverse and accepting of the “weird, eccentric, or idiosyncratic.” Some students with ASD report finding a peer group at college for the first time in their lives. At college it is acceptable to organize one’s social life around special interests or passions. This may happen through a program major or through social clubs or groups. There are also a multitude of ways to connect with others through activities that are enjoyable, such as attending films and productions, playing pool, playing chess, and attending sports events. College graduates with

Chapter 2

ASD have commented that they have gained a greater understanding of social rules and a better ability to communicate.

There are websites with recommendations of user-friendly colleges for the autism spectrum, online chat rooms for college students on the spectrum, and important articles and resources through autism organizations. Area autism support groups sometimes have practical experience and tips to share.

Books and Articles Especially for College Students with ASD with Advice from Peers

One useful website is that of University Students with Autism and AS (<http://www.users.dircon.co.uk/~cns/>). Another university offers an e-booklet of advice for students with Asperger's called *Towards Success in Tertiary Study with Asperger's Syndrome and Other Autistic Spectrum Disorders*, available at <http://www.services.unimelb.edu.au/ellp/publications/towards.html>.

An article called "The Hindered Path" was originally written by Laura Tiffany for the student newspaper at Memorial University. It describes the postsecondary experience for individuals on the autism spectrum. It can be found at <http://www.users.dircon.co.uk/~cns/article.html>.

Lars Perner, Ph.D., wrote "Preparing to Be Nerdy Where Nerdy Can Be Cool: College Planning for the High Functioning Student with Autism" found at <http://www.professorsadvice.com/>. This same website has a reprint of an article from the 2003 issue of *Autism-Asperger's Digest* on selecting a college for a person on the autistic spectrum (see <http://www.larsperner.com/autism/colleges.htm>). It includes specific details about services offered and contact persons for specific colleges.

In 2004, *Succeeding in College with Asperger Syndrome: A Student Guide* made its debut. John Harpur, Maria Lawlor, and Michael Fitzgerald state that their primary purpose for the book is to "assist those with AS cope with the challenges life brings" and add that the book is also helpful for parents, counselors in student

services, and therapists. Another current recommendation for students on the spectrum thinking about college is *Aquamarine Blue 5: Personal Stories of College Students with Autism* edited by Dawn Prince-Hughes (Swallow Press, 2002).

Bridging from College to Work

Departure from college is another major transition. While postsecondary education and training provide valuable credentials, a college degree does not guarantee employment for any student. Work experiences throughout the college career help students prepare for the transition. A student can request help from VR with summer jobs, volunteer opportunities, and/or part-time employment. At college, there are possibilities such as participation in work-study programs, research projects in the student's department or major, and career fairs. Many college programs or majors include internship requirements where students not only develop practical skills in their field, but also develop connections to future jobs. At graduation, VR joins forces with the student to complete the bridge to employment.

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APPENDIX B

PLANNING FOR VOCATIONAL DEVELOPMENT

For: _____

Date: _____

Target vocational goal for post-high school (number of hours/day;
number of days/week):

Key players involved in vocational activities and program:

Personal Profile

Communication mode(s):

Enjoyable activities for the student:

Personal strengths (i.e., matching, color identification, sorting,
stapling, etc.):

Past employment or work experiences:

Medical and safety issues/concerns:

Vocational Profile

Preferred environments and comfortable, productive contexts:

Pleasurable rewards for the student:

Behavioral triggers/environmental irritants and signs/signals of
escalating discomfort:

Key behavioral signals of happiness and satisfaction:

Possible job tasks to try that have a high likelihood of success:

APPENDIX C

TEN THINGS YOUR STUDENT WITH AUTISM WISHES YOU KNEW

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Author's note: When my article Ten Things Every Child with Autism Wishes You Knew was first published in November 2004, I could scarcely have imagined the response. Reader after reader wrote to tell me that the piece should be required reading for all social service workers, teachers and relatives of children with autism. "Just what my daughter would say if she could," said one mother. "How I wish I had read this five years ago. It took my husband and I such a long time to 'learn' these things," said another. As the responses mounted, I decided that the resonance was coming from the fact that the piece spoke with a child's voice, a voice not heard often enough. There is great need—and I hope, great willingness—to understand the world as special needs children experience it. Ten Things Every Child with Autism Wishes You Knew became a book in 2005, and now the voice of our child returns to tell us what children with autism wish their teachers knew.

1. Behavior is communication. All behavior occurs for a reason. It tells you, even when my words can't, how I perceive what is happening around me. Negative behavior interferes with my learning process. But merely interrupting these behaviors is not enough; teach me to exchange these behaviors with proper alternatives so that real learning can flow.

Start by believing this: I truly do want to learn to interact appropriately. No child wants the negative feedback we get from "bad" behavior. Negative behavior usually means I am overwhelmed by disordered sensory systems, cannot communicate my wants or needs or don't understand what is expected of me. Look beyond the behavior to find the source of my resistance. Keep notes as to what happened immediately before the behavior:

people involved, time of day, activities, settings. Over time, a pattern may emerge.

2. Never assume anything. Without factual backup, an assumption is only a guess. I may not know or understand the rules. I may have heard the instructions but not understood them. Maybe I knew it yesterday but can't retrieve it today.

Ask yourself:

- Are you sure I really know how to do what is being asked of me? If I suddenly need to run to the bathroom every time I'm asked to do a math sheet, maybe I don't know how or fear my effort will not be good enough. Stick with me through enough repetitions of the task to where I feel competent. I may need more practice to master tasks than other kids.
- Are you sure I actually know the rules? Do I understand the reason for the rule (safety, economy, health)? Am I breaking the rule because there is an underlying cause? Maybe I pinched a snack out of my lunch bag early because I was worried about finishing my science project, didn't eat breakfast and am now famished.

3. Look for sensory issues first. A lot of my resistant behaviors come from sensory discomfort. One example is fluorescent lighting, which has been shown over and over again to be a major problem for children like me. The hum it produces is very disturbing to my hypersensitive hearing, and the pulsing nature of the light can distort my visual perception, making objects in the room appear to be in constant movement. An incandescent lamp on my desk will reduce the flickering, as will the new, natural light tubes. Or maybe I need to sit closer to you; I don't understand what you are saying because there are too many noises "in between"—that lawnmower outside the window, Jasmine whispering to Tanya, chairs scraping, pencil sharpener grinding.

Ask the school occupational therapist for sensory-friendly ideas for the classroom. It's actually good for all kids, not just me.

4. Provide me a break to allow for self-regulation before I need it.

A quiet, carpeted corner of the room with some pillows, books and headphones allows me a place to go to re-group when I feel overwhelmed, but isn't so far physically removed that I won't be able to rejoin the activity flow of the classroom smoothly.

5. Tell me what you want me to do in the positive rather than the imperative. "You left a mess by the sink!" is merely a statement of fact to me. I'm not able to infer that what you really mean is "Please rinse out your paint cup and put the paper towels in the trash." Don't make me guess or have to figure out what I should do.

6. Keep your expectations reasonable. That all-school assembly with hundreds of kids packed into bleachers and some guy droning on about the candy sale is uncomfortable and meaningless to me. Maybe I'd be better off helping the school secretary put together the newsletter.

7. Help me transition between activities. It takes me a little longer to motor plan moving from one activity to the next. Give me a five-minute warning and a two-minute warning before an activity changes—and build a few extra minutes in on your end to compensate. A simple clock face or timer on my desk gives me a visual cue as to the time of the next transition and helps me handle it more independently.

8. Don't make a bad situation worse. I know that even though you are a mature adult, you can sometimes make bad decisions in the heat of the moment. I truly don't mean to melt down, show anger or otherwise disrupt your classroom. You can help me get over it more quickly by not responding with inflammatory behavior of your own. Beware of these responses that prolong rather than resolve a crisis:

- Raising pitch or volume of your voice. I hear the yelling and shrieking, but not the words.
- Mocking or mimicking me. Sarcasm, insults or name-calling will not embarrass me out of the behavior.
- Making unsubstantiated accusations

- Invoking a double standard
- Comparing me to a sibling or other student
- Bringing up previous or unrelated events
- Lumping me into a general category (“kids like you are all the same”)

9. Criticize gently. Be honest—how good are you at accepting “constructive” criticism? The maturity and self-confidence to be able to do that may be light years beyond my abilities right now. Should you never correct me? Of course not. But do it kindly, so that I actually hear you.

- Please! Never, ever try to impose discipline or correction when I am angry, distraught, overstimulated, shut down, anxious or otherwise emotionally unable to interact with you.
- Again, remember that I will react as much, if not more, to the qualities of your voice than to the actual words. I will hear the shouting and the annoyance, but I will not understand the words and therefore will not be able to figure out what I did wrong. Speak in low tones and lower your body as well, so that you are communicating on my level rather than towering over me.
- Help me understand the inappropriate behavior in a supportive, problem-solving way rather than punishing or scolding me. Help me pin down the feelings that triggered the behavior. I may say I was angry but maybe I was afraid, frustrated, sad or jealous. Probe beyond my first response.
- Practice or role-play—show me—a better way to handle the situation next time. A storyboard, photo essay or social story helps. Expect to role-play lots over time. There are no one-time fixes. And when I do get it right “next time,” tell me right away.
- It helps me if you yourself are modeling proper behavior for responding to criticism.

10. Offer real choices—and only real choices. Don’t offer me a choice or ask a “Do you want . . . ?” question unless you are willing to accept no for an answer. “No” may be my honest answer to “Do

Chapter 2

you want to read out loud now?” or “Would you like to share paints with William?” It’s hard for me to trust you when choices are not really choices at all.

You take for granted the amazing number of choices you have on a daily basis. You constantly choose one option over others knowing that both having choices and being able to choose provides you control over your life and future. For me, choices are much more limited, which is why it can be harder to feel confident about myself. Providing me with frequent choices helps me become more actively engaged in everyday life.

Whenever possible, offer a choice within a “have-to.” Rather than saying: “Write your name and the date on the top of the page,” say: “Would you like to write your name first, or would you like to write the date first?” or “Which would you like to write first, letters or numbers?” Follow by showing me: “See how Jason is writing his name on his paper?”

- Giving me choices helps me learn appropriate behavior, but I also need to understand that there will be times when you can’t. When this happens, I won’t get as frustrated if I understand why:
 - “I can’t give you a choice in this situation because it is dangerous. You might get hurt.”
 - “I can’t give you that choice because it would be bad for Danny” (have negative effect on another child).
 - “I give you lots of choices but this time it needs to be an adult choice.”

The last word: believe. That car guy Henry Ford said, “Whether you think you can or whether you think you can’t, you are usually right.” Believe that you can make a difference for me. It requires accommodation and adaptation, but autism is an open-ended disability. There are no inherent upper limits on achievement. I can sense far more than I can communicate, and the number one thing I can sense is whether or not you think I “can do it.” Expect more and you will get more. Encourage me to be everything I can be, so that I can stay the course long after I’ve left your classroom.

Chapter 3

ACCESSING THE VOCATIONAL REHABILITATION SYSTEM

By Carol Quirk, Lu Zeph, and Don Uchida

This chapter presents a picture of the impact of autism spectrum disorders (ASD) on the process of accessing vocational rehabilitation (VR) services and developing the individualized plan for employment (IPE). As a result of reading this chapter, the VR counselor will be able to (a) make considerations for the initial intake, (b) design methods for obtaining assessment information, (c) know what to consider in a job search, and (d) know how to select and design strategies, job accommodations, and supports.

ASD is a complex neurological disorder affecting social interactions, communication, and adaptive responses to environmental stimuli. Although ASD may change over the lifetime of an individual, it is a lifelong disability. The majority of individuals who have been given an ASD diagnosis require supports and services to become gainfully employed. It is the task of the VR counselor to determine if individuals are eligible for VR services and, if so, to assess their needs, establish goals, and define the services that will be needed to obtain and maintain a job.

Outreach

In 2003 in the United States, a total of 1,172 people with the label of “autism” were reported as being eligible for VR services, had an employment plan developed, and exited the VR system. Of these,

Chapter 3

719 individuals were successfully employed, as measured by the total number of “closed” cases reported. This number has increased in the last 2 years, but it is deplorably low: less than 2,000 people with autism nationally received VR services in 2005, and less than 1,200 of these individuals were successfully employed (data provided by the Rehabilitation Services Administration of the U.S. Department of Education). If we consider the current estimate of at least 1 in 150 persons being diagnosed with autism, as cited by the Centers for Disease Control and Prevention (2007), the number of adults who may have ASD and who may be in need of VR services is vastly greater than 2,000 people. While it may be true that some individuals with ASD have in fact been served by VR agencies but were reported under another disability label, most people with ASD remain unserved and underserved.

For a long time it has been assumed that individuals with autism were unlikely to be successful in employment. Despite abundant evidence that they can be successfully employed, individuals with ASD continue to report substantial difficulty with obtaining and retaining successful jobs (Hagner & Cooney, 2005; Hurlbutt & Chalmers, 2004). With the advance of research on effective strategies, new technologies, and the creative use of support services, more and more individuals with ASD can benefit from VR services (Schaller & Yang, 2005). We now have a better understanding of the characteristics that affect people with an ASD diagnosis, the means to develop more effective communication systems, and the knowledge to design effective supports that lead to a satisfying life in the mainstream of the community. With the ever-growing number of children being diagnosed with ASD who will soon be exiting the public school system, it is essential that VR counselors reach out to their communities, schools, and other service providers to identify individuals with ASD in need of VR services. VR counselors need to understand how the characteristics of autism influence job matching and the design of an employment environment so that the person will be successful.

Intake and Eligibility Determination

Individuals with an ASD diagnosis present a variety of skills, abilities, and needs. However, the factor that cuts across all ASD

labels is difficulty with social interactions and interpersonal communication, as well as restrictive repetitive behaviors and interests. In addition, the person with ASD may be unmotivated to cooperate with requests, become anxious under certain sensory or emotional conditions, display impulsive behavior that may be inappropriate to the situation, or use an unconventional communication system. What may appear to be “noncompliant” behavior may not actually be a “refusal” to follow direction but may result from difficulties with auditory processing, a lack of motivation, an inability to switch from one task to another, a difficulty producing the correct motor response or initiation, or an incorrect interpretation of the request. The very characteristics associated with the ASD diagnosis may make assessment of VR needs and services even more challenging for the VR counselor, since most information is gathered by interacting with and requesting responses from the potential VR client!

When exiting the public school system—where their parents were an integral part of their educational planning team—individuals with ASD may not be prepared to be their own advocate. Regardless of clients’ age, it is often helpful if someone who knows and cares about them comes to the initial intake meeting to assist in communicating information, identifying choices, etc. This may be a parent or guardian, a trusted friend or relative, or an advocate who is interested in the person’s welfare. The VR counselor may want to encourage the person to identify someone whom they trust to contribute to the intake and assessment process. According to some VR counselors:

I have found that it really helps to have a family member or someone who has known the person from childhood to adulthood present to help me to identify and understand how this person communicates, essentially teaching me how to talk to their son or daughter.

R. displayed significant communication problems, both verbally and nonverbally. He is essentially noncommunicative, except with his mother. He does not maintain eye contact, does not face the speaker, and holds his head down, with eyes downward. R. responds only at

Chapter 3

the prodding or gentle command from Mrs. B. I have to speak to him through her.

One of my clients does not pick up on nonverbal cues, like knowing to stand up and leave when I tell him we're all finished. I need to remember to specifically tell him what to do and I need to remember not to use idioms or local expressions, because—as smart as he is—he just doesn't get it.

Most individuals with autism are diagnosed before the age of 3. Nonetheless, the diagnosis of autism in and of itself offers little to provide an understanding of a particular individual. Due to the atypical neurological processes of individuals with autism, standardized assessment instruments are not usually very helpful. Based on testing and observation of functional performance, it has often been assumed that an individual with autism also had an intellectual disability. It has become clear that persons with the ASD label do not perform well in standard test situations and, when they find a means to adequately communicate and when they are in emotionally supportive environments, they display far greater intellectual capacity than was thought. Concurrent conditions such as obsessive-compulsive disorders and Tourette's syndrome may also be present. Any intake process will require that VR counselors understand the impact of autism and be able to obtain and interpret information from other evaluators.

Some VR counselors described challenges to accurate diagnosis:

I just had a client tested for attention deficit disorder (ADD) and learning disabilities (LDs), which he said he had. But I asked the evaluation center to also check for Asperger's syndrome. He was diagnosed with Asperger's syndrome, but no LD or ADD. He had been misdiagnosed earlier in his life and had no idea he had Asperger's until now.

My client was misdiagnosed for years. Finally a neuropsychological evaluation accurately came up with Asperger's syndrome, but he had been diagnosed as being

mentally retarded. I have him in regular college now, but he has some behaviors that are hard for others to watch (picking his face, for example). For all these years, it was assumed that he couldn't learn much of anything, and communicating with him is very difficult.

L. came out of school with the wrong diagnosis. She had been considered a behavior problem with mental retardation. However, she has autism: she tends to immerse herself in an activity, almost compulsively, and it is very hard to get her to change tasks.

Eligibility is determined by reviewing existing information from other programs or service providers, from the family, from existing evaluations, and through the assessment process that includes trial work experiences *of sufficient variety, with appropriate and sufficient supports, over a reasonable length of time*. An individual with ASD is eligible for VR services if the symptoms constitute a substantial impediment to employment and he or she requires VR services to prepare for, secure, retain, or regain employment. Any person who is a beneficiary of Supplemental Security Income or Social Security Disability Insurance is presumed to be eligible for VR services.

Eligibility determinations must be made within 60 days of the application for VR services unless there is a signed agreement between the individual and the counselor for a specific extension of time (e.g., an additional 60 or 120 days). Extensions would occur when there are exceptional circumstances, such as the need for additional time to obtain adequate diagnostic information, gather assessment information, or obtain assistance in interpreting the information. If more information is needed, the VR counselor may need to contact the local health department, a hospital that specializes in medical or intervention services for people with autism, the local school system's special education department, or a university in the state that has a department on disability issues (in the school of education or another school).

Chapter 3

Sometimes a person with ASD can be so high functioning that the counselor may not be sure if the person is truly in need of VR services. It may appear that the disabling condition will not impede employment. The counselor will need to look at the medical documentation and get input from the person as well as others who know him or her to identify any of the characteristics of the disability that may interfere with obtaining or retaining a job. Alternatively, a person with ASD can appear to be so low functioning that the counselor may not believe that the person could achieve an employment outcome. Often, it is the communication difficulties or lack of an effective communication system that makes the person appear more disabled than he or she actually is.

Before assuming ineligibility and closing the case as unfeasible for successful employment, the VR counselor needs to set up a variety of trial work experiences with a variety of appropriate and sufficient supports. Any determination of ineligibility must include clear and convincing evidence that the individual is not capable of achieving employment, with documentation that

- Will stand up in court
- Demonstrates a high degree of certainty that the person is incapable of benefiting from services
- Is unequivocal (is strongly suggested from a variety of sources)
- Includes a description of assessment information
- Includes a functional assessment of skill development activities with the necessary supports (such as assistive technology), in real-life settings

Not every person who has a diagnosis of ASD will need to use VR services, but most will. And while most individuals with ASD can be successfully employed, there will very likely be a need for long-term support and services to maintain that employment. The social and communication differences that are part of the disorder, even without additional difficulties, may prevent the person from getting and/or keeping a job without some form of assistance such as on-the-job training and creation of a supportive work environment. In

the planning process, the VR counselor should consider the appropriateness of Plan for Achieving Self-Support (PASS), Impairment-Related Work Expenses (IRWE), and other funding opportunities to assist with expenses such as technology, transportation, and other supports and services related to successful employment.

Assessment Process

Diagnosis is only the starting point of the assessment process. Once diagnostic testing is obtained and the individual is determined to be eligible for VR services, additional assessment takes place. A comprehensive assessment will take into account the individual's communication method, comprehension of abstract concepts versus literal interpretation, social skills, adaptive behavior, need for structure and routine, response to stressful situations, and responsiveness and/or sensitivity to sensory input, as well as the impact of other co-occurring conditions that might be present. Given these considerations, the vocational assessment will determine job possibilities based on preferences and skills, identify the job/employment skills that the person has and needs to learn, identify the supports needed through VR to be successful, identify the changes expected as a result of job skill preparation and on-the-job supports, and determine the person's ongoing support needs and sources of assistance once employment is obtained.

Since communication and social skills are affected by this disability, in most instances the VR counselor will need additional input from family members or other caring and concerned people who know the person. A comprehensive approach is needed that combines a variety of processes including interviews, input from family or others who know the person best, observation of the individual in his or her typical environments, and a functional skills assessment. An experienced evaluator who understands autism in its many forms can collect data related to what the individual is able to do in each environment and can observe firsthand how the person approaches the world. Observing the student performing in a variety of social and work environments and in the company of trusted people versus new and unfamiliar

Chapter 3

settings will be critical. Considering the nature of the disability and the importance of involving those who know and care about the client, VR counselors should take an individualized person-centered planning (PCP) approach. If the person presents challenging behavior, then the VR counselor needs to enlist those who know and care about the person to conduct a functional behavior assessment. These strategies and considerations for conducting traditional assessments are discussed below.

Person-Centered Planning

PCP begins by creating a team of people identified by the person with a disability who know and care about the person and are willing to come together to develop a plan for the person's future. The family and friends play a pivotal role: besides knowing the person best, they will often be the primary supports to the person outside of work. Since persons with ASD may exhibit behavior that is unusual or even startling to those who don't know them, it is critical that planning begin with a commitment to get to know and understand the person.

The focus of PCP is often much broader than employment possibilities. It usually addresses the variety of needs for increased participation in life as an adult. It is a first step to developing a plan of action that will lead to the development of goals and identification of the supports and services needed to achieve those goals. The advantage of this approach is that it considers the service from the vantage point of the individual with the disability instead of from the system's view and it encourages the participation of family and other community members to organize and provide the supports necessary to make that dream a reality. For persons with ASD and other significant disabilities, this approach can have a serious effect on the quality of the employment plan that will be developed. It enlists the participation of people who are critical to the individual of concern; they identify what it would take for the person to have a successful and satisfying life, and the action plan they develop should address the functional limitations that the person experiences as well as the person's strengths and interests.

There are several PCP processes, such as *Making Action Plans*, known as MAPS (Forest & Lusthaus, 1990); *Group Action Planning*, known as GAP (Turnbull & Turnbull, 1992); and *Planning Alternative Tomorrows with Hope*, known as PATH (Pearpoint, O'Brien, & Forest, 1993). While each of these approaches has a unique orientation, they all involve identifying a circle of people who care: family members, friends, peers, and service providers. The groups usually meet at least twice. Initially they share information and identify first steps toward action planning. Then they work with the facilitator (VR counselor) to develop a comprehensive plan for the individual's future. PCP offers a holistic approach to vocational planning that allows issues such as housing, transportation, accommodations, relationships, and future aspirations to be considered. While these areas may not be within the purview of traditional VR, they often affect the success or failure of attaining a person's vocational goals.

Whether the team uses an existing PCP process or creates its own variation, the central theme of the PCP is that the person who is the subject of the planning is the key participant. It gives the notion of "informed choice" more meaning, as the person is central to the process. The individual identifies who should participate and where the meeting should take place. A facilitator familiar with the principles of PCP should run the meeting. That facilitator will have prepared a few questions for discussion and have chart paper for each question posted for all to see. During the sessions, no reports are given and no scores are discussed. A recorder assists by noting everyone's input and makes sure that the descriptive notes of the meeting are later shared with participants. The process typically addresses several questions:

- *Who is J* (the potential employee and VR services consumer)? Beginning with the person and his family, basic information is solicited such as his age, history of services, physical concerns, preferred and most effective communication mode, personal characteristics, stressors, etc. Information may include the characteristics that led to the diagnosis of autism and how this has affected his life.

Chapter 3

- *What does J like and dislike?* Information about his preferred activities, people, ways to interact, or other things that bring enjoyment will be valuable to consider when looking for job characteristics that may be a good fit. Information about what is aversive, uncomfortable, or least preferred for the individual will help in considering accommodations or modifications that may need to be designed in potential work settings. This may be most helpful in job matching or job design, considering the likelihood that a person with ASD may have sensory sensitivities, become anxious in certain social situations or environmental conditions, and have favorite topics or behaviors that could translate into a job talent.
- *What is J's current situation?* There may be factors in the individual's home, personal support system, financial security, or other aspects of his present life that may impact his ability to get to work, arrive "ready to work," stay at work, or handle work stresses.
- *What are J's hopes and dreams for the future (or more specifically for his employment)?* The hopes and dreams for the person's future may or may not match up with the living or work situations that may seem possible. The answer, however, will help to shape the direction for seeking employment or identify the services that might be required to prepare the person for employment.
- *What are J's fears and nightmares for the future?* This question may not be often asked, but the answers may bring up information that would not otherwise be obtained. For example, one client's family said that they were afraid that their son would be bullied by coworkers. Since they also hoped that their son would develop friendships, this information helped the VR counselor begin thinking immediately of the peer relationships that might need to be considered as they conduct a job search and look to match a job environment to the client's needs. The social scene in job sites will be a critical consideration for both supports and potential problems for the person with ASD.

- *What works for J?* The smallest things may be the most important, and the family or friends of the client may know best what supports will prevent problem behavior, motivate the person's participation on the job, and increase the likelihood of success. When family and friends have identified successful support strategies for the person with ASD, the VR counselor will want to begin thinking about how these could translate into on-the-job supports.
- *What are J's gifts and talents?* Especially when a person presents unique challenges, it is tempting to focus on those challenges (behavior, communication, functioning level, etc.) rather than the person's strengths. It could be that, when answering this question, the counselor may discover that J has a passion for organizing things alphabetically or is a talented musician. If a job is found that capitalizes on the person's strengths, it has the potential for increasing that person's value to those in the work environment.
- *What else should we consider in our future plan: home, work, learning, community?* There are other connections that may be very important in giving the person with ASD the opportunity for a satisfactory life. When life offers less stress and more satisfaction, consumers with ASD (and all of us!) are more likely to be successful. Areas that might be discussed in terms of interests and needs are relationships; recreation/leisure activities; volunteer opportunities; art/cultural activities; spirituality; shopping; transportation; and physical health, mental health, and wellness services.

Based on the answers provided, a picture develops that will help to define employment goals, the VR services that will be needed, and other aspects of the person's life that will enhance his or her ability to keep a job. With the VR counselor, the team identifies any additional information that should be gathered, any testing that might take place, and the initial action steps to support the person being discussed. The team agrees to come together again at a later date to compare their progress and make adjustments or suggestions for the IPE to promote successful employment and life participation.

Chapter 3

Considerations for Traditional Assessment and Trial Work Experience

Existing assessments or other relevant information from the applicant's school or other programs or providers will give some initial information. The assessment process should include observations, anecdotal information, on-the-job try-outs, tests, and work samples. It provides information on career development background, interests, aptitudes, special needs, learning style(s), work habits and behaviors, personal and social skills, values and attitudes towards work, self-concept, and work tolerances. Several professionally developed functional assessment inventories, checklists, and interview forms have been developed to evaluate areas such as using transportation, independent living and decision-making skills, and interpersonal relationships. These may include, for example, situational assessments, interest inventories, temperament inventories, learning style inventories, and work samples.

It is important for the VR counselor to be able to assess the person's performance in a variety of social situations and different applied work environments. The person with ASD is likely to perform very differently under different social, sensory, and physical conditions. Obtaining information on the person's skills within natural settings (home, community, and potential job sites) as well as how the individual accommodates to each environment is important. Direct observation by an experienced evaluator assists in analyzing the demands of different environments and provides real insights into the individual's support and accommodation needs. It is critical to document not only what the person can or cannot do independently, but also *what supports and strategies prevent problem situations, and what works to assist the person to function in that setting*. Some considerations are communication, prompting, eye contact, getting answers to questions, getting response to requests, repetitive movements, movement and sensory differences, dealing with anxiety, and teaching social skills.

Communication. It is essential that, during assessment as well as during job training, the counselor know and use the individual's preferred mode of communication. This mode may be manual

signs, the printed word, a communication device or board, or another form of alternative technology. To get a good idea of the person's real functional abilities, a supportive emotional environment is important. Since auditory processing may be a problem, the individual will need clear and direct instructions and time to process the information and to respond. Be clear. Do not ask open-ended questions unless you are sure that the person is able to respond to them. If you offer choices, then be ready to accept the response. For example, if you say, "Do you want to start this test now?" then the answer may be no. Be clear on the directions: "Next we will. . . ." Consider creating a visual sequence (in words or graphics) of the interview/testing situation, so the individual can predict and plan for what comes next. Repeating instructions over and over is not a good strategy. Besides being frustrating to the counselor, it may increase the anxiety of the person being assessed and will not increase comprehension of the direction.

Prompting. Some individuals respond well to a physical prompt to initiate performance of a task, and then they can complete the required steps. Other individuals may need a visual model of the sequence of steps (for example, picture cues or an actual physical model), and that is sufficient to follow a sequence of directions or steps to complete an activity. Sometimes, by providing prompts and attempting to fade them, the extent of assistance and ease of fading prompts can be assessed. For individuals with ASD, it is critical that the evaluator know the person's learning style and how he or she reacts to various cues and sensory input. For example, a verbal prompt may be distracting to some people and helpful to others. A physical prompt may be intolerable to a person with tactile sensitivities. Most individuals with ASD respond better to a familiar and trusted person than to someone who does not know or understand them.

Eye contact. Some, but certainly not all, persons with ASD avoid eye contact. The individual with ASD may actually orient himself away from the interviewer. Do not interfere with this behavior, as it may be a person's way of accommodating to the situation. Avoid trying to turn the head of the person, and do not repeatedly ask the person to "look at me." As noted by a young man with autism:

Chapter 3

Though I can read, when I look at a page in a book the print fragments; I need to alter my focus by looking away. . . . I know that I need to look directly [at people]. I just find it hard. It frightens me. I feel like I am submersing myself in the other person.

Another high school student with autism noted:

Sometimes eye contact unsettles my focus as I begin only to think of series of things as connected to eyes, a color perception, soul, and eye connection to their brain systems. Talk about getting off task!

Getting answers to questions. Some individuals find abstract and colloquial phrases confusing and may interpret them literally. There may be difficulty with “wh” questions. Once on a topic, they may not be able to change topics if they have more to say about the first one. Or they may simply not want to change to another, less preferred topic. For many individuals, there is a need for longer time to process verbal questions. Don’t ask questions right away. Do *explain* to the person—using clear, concise, concrete language—what is going to happen and what you would like him or her to do. Tell the person when you are going to ask a question. Resist the temptation to repeat the question without adequate wait time, and do not ask a series of questions, expecting the person to remember each one and answer in sequence. One VR counselor reported:

B. has a hard time focusing and listening, but has no problem talking. I’ve found that sitting and allowing her to talk and talk is not the answer. I had to set boundaries before the conversation, for example saying: “We are going to talk about X. But first I will explain Y.” After explaining what we were talking about, I then asked her specific questions and helped her focus throughout the conversation by reemphasizing the topic we are currently discussing.

Once you have asked a question, *wait*. Individuals with ASD often need additional time after being spoken to before they can respond. Be careful not to add quick additional verbal information while the

individual is processing what you have already said. A student with autism told us:

It is a big deal to know when [someone] is going to pose a question. For me, I must have advance signals, as I must type a response. I also need time to formulate the answer, sorting through my systems to choose whether it's stored in memory or requires a new formulation. . . . [I need] patience and consideration for all the systems trying frantically to work together. You must give enough time to process. Waiting time is a courtesy given to me as an intelligent person.

Getting response to requests. A person with ASD might not respond to a request that is made—and the lack of response may not be due to “noncompliance.” It could be that there has not been enough time to process the request, the request was confusing, or there were competing needs (fear, anxiety, sensory overload) or difficulty with making the body respond. Some people with autism who have written about their perceived “noncompliance” explained how their movement differences affect their engagement with the world around them:

I am utterly trapped in my body. Making it move to respond to a request is hard. Some . . . will not know where your legs are. Others will find that their legs will start moving and not stop. Your lips feel numb, sometimes you sound too loud, and your tongue is out of time with the other parts of your mouth. Yes, it is embarrassing.

Be prepared to *follow up* with a response and not a repetition of the question. Don't ask the person to do something unless you are going to be ready to help her or him respond, comply, refuse, or negotiate. If you want the person to come into your office, for example, and you say, “Come here please” but he does not come in, then you need to get up, go to the person, and find out what is needed to help him move into your office. *Give choices* as often as possible. Sometimes you may not understand and may never find out why a person is not responding to your request.

Chapter 3

Repetitive movements. Some individuals may engage in repetitive movements that may be annoying to the interviewer/evaluator. They are probably annoying because they are distracting, or because they involve hand movements and individuals may need to use their hands in order to respond. We should understand that these are adaptive responses to individuals' internal needs, and they are only annoying to us. According to a young man with autism:

[Repetitive movements] are not a lousy thing. You see, I think of it as you drinking coffee or tea, or having that all-important phone near you. . . . I notice my mom taps her front tooth in thought, and I think that looks slightly weird to me. It is . . . a bit of anxiety coming to settle. . . . [I am] limited in every way by the overwhelming anxiety that I feel. My anxiety has no precipitating reason. It shows itself in my wringing hands, also my pacing, running, and general hyperactivity.

Ask others who know the person with ASD how they respond when the individual engages in movement that interferes with attention to or performance of a task. This can be discussed during an initial interview with the family or the person, or during the information-gathering part of a PCP session. Giving a light touch, tapping an item for mutual attention, or making another attempt to redirect the person might “work” to get him to stop an interfering movement. Or it may be intrusive and raise the anxiety of the individual. If the movement doesn’t really interfere, then it may just be something that everyone agrees to ignore!

Movement and sensory differences. Movement differences may be manifested by an unusual gait or posture, constant physical movement, episodic physical agitation, or repetitive behaviors. Other movement differences can be evident in relation to an activity, such as difficulty with initiating an action (such as walking down a hall), maintaining the rate or rhythm of movement, stopping an action (which may be interpreted as “perseverating” on it), or doing two things at once (listening to someone speak while looking at their face) (Amos, 1999). A person with ASD who uses words to communicate may experience very similar difficulties in

speech. Beginning a sentence, translating a sequence of thoughts into a sequence of sentences, maintaining the rate and rhythm of speech, stopping discussion of a topic, or trying to maintain a discussion while other people interrupt can be very difficult. The employer and coworkers will need to understand these differences and the energy that it takes for a person with ASD simply to make it through the day.

Dealing with anxiety. A variety of factors that may not be clearly discovered can result in anxiety and stress for the person with ASD. Stress is one of the most overlooked problems in autism (Baron, Lipsitt, & Goodwin, 2006) and is thought to be a direct result of how the person with autism experiences the world. The stressors may be related to environmental, social, or internal demands (Grodén, Levasseur, & Goodwin, 2006). Signs of stress may be seen in an increase in repetitive movements, repeated words, agitated movements, or even aggression toward self or others. The person will need to develop coping techniques to prevent anxiety and respond appropriately in these situations. This is what *not* to do:

- Start to make demands
- Relate this situation to others in the past
- Lecture
- Identify consequences to the situation (it will sound like a threat)
- Engage in other nagging verbal behavior
- Physically intervene unless the individual is aggressive in an uncontrolled manner

What the counselor or job coach *can* do:

- Pay close attention to what the person may be communicating
- Allow more time to process information
- Give clear and simple directions
- Use a soft and calming voice
- Model ways to express the need for a break
- Break down the task into simpler steps

Chapter 3

- Identify sensory difficulties that may be present and make adjustments
- Offer choices
- Return the person to a familiar setting

Teaching social skills. Individuals with autism may not be able to attend to social cues and may have difficulty interpreting social interactions, including facial expressions, gestures, and speech (Dawson, Meltzoff, & Osterling, 1995). They may need explicit instruction in what features of the social environment to notice and how to attend to other people. They may need someone to explain the behavioral expectations of potential social situations that will be encountered on the job. Very specific skills, such as knowing how far away to stand when in conversation or when to stop talking about a favorite subject, can be taught.

Functional Behavior Assessment

Applied Behavior Analysis (ABA) provides a scientific and conceptual framework for looking at how behaviors are learned, why behaviors are used, and how to change them. In a traditional view of modifying behavior, those who understand ABA principles design interventions to stop or teach behavior. A new branch of this science incorporates this knowledge and moves beyond it to address a more comprehensive lifestyle change (not just behavior management) so that the individual does not need to use the problem behavior and his or her overall quality of life is enhanced (Carr et al., 2002). Thus we have the applied science of positive behavior supports to help an individual achieve his or her goals in a socially acceptable manner and to reduce the effectiveness of and the need to use problem behavior to achieve goals. For the person with ASD who is seeking employment, the counselor will want to be familiar with strategies to assess the function of challenging behavior so that the team can develop positive supports to assist the individual in developing behavior that will enhance the likelihood of employment success.

The emphasis in positive behavior supports is prevention: by assessing the function that the problem behavior serves (e.g., avoidance, attention-seeking, need for control), interventions can

be designed to (a) serve that function and decrease the need for using the problem behavior (supports for prevention), (b) teach alternative ways to communicate the need (replacement behavior), and (c) respond in a way that minimizes the effectiveness of the problem behavior. The key will be in conducting a quality functional behavior assessment to understand what motivates the individual, what events are likely to trigger the behavior, as well as what makes the problem behavior effective. The functional behavior assessment process involves three steps:

1. *Gathering information.* From records, observations, analysis of the circumstances under which the behavior occurs and doesn't occur, interviews, etc., the VR counselor can work with the individual's team to describe
 - The events that make the behavior more likely to occur (e.g., when tired, after a conflict with a family member, under noisy conditions)
 - The immediate triggers that are likely to precede the problem behavior (e.g., task demands, presence of an unfamiliar person)
 - General motivations that strongly influence the person (e.g., avoidance, attention)
 - Consequences that are likely to follow and serve to maintain the behavior (positive or negative reinforcers of the behavior)
2. *Hypothesizing* the conditions under which the behavior is likely to occur.

Example 1: Marty is a verbal young man who works in a video store. When he doesn't understand his task or when the directions are complex, he walks to the back of the store and talks to himself, pacing back and forth (problem behavior). He will not respond to requests to return to the front so that his supervisor can explain the task and may stay in the back for almost an hour. This is more likely to occur when he has not had enough sleep or if he has had an argument with a family member.

Example 2: Sandra shouts "No!" and ignores directions when asked to redo clerical work (filing or typing) when there are errors. Her office manager usually continues to repeat

Chapter 3

directions and gets very annoyed with her, often sending her to the break room and telling her to return when she is willing to do her work correctly. When in the break room, Sandra calms down and enjoys talking to her coworkers. The problem behavior is more likely to occur on Mondays after spending the weekend home alone and is more likely to occur when she has been working for a long period without a break.

3. *Putting preventive measures in place and observing the behavior to determine if the hypothesis is correct.* For example, if the above hypotheses were correct, clearer directions may prevent Marty from walking away. Giving Sandra extra attention on Monday mornings before she starts work, providing her with a schedule for doing and checking her work, and reminding her that she can take a break with coworkers at a regularly scheduled break time may encourage her to reduce errors.

Based on this information, the VR counselor should work with the team and potential employer to develop a plan for positive behavior supports. The plan would include three elements:

- *Teaching plan.* Specify the steps for teaching and reinforcing alternative behaviors (e.g., teach Marty to ask for help when he is unclear of his task; teach Sandra to ask for a break when she needs one, with time limits for her return).
- *Support plan.* Identify preventive supports to avoid the use of the behavior (e.g., clear verbal directions with a visual task schedule for Marty; morning attention and built-in breaks for Sandra as well as explicit feedback on quality of work).
- *Response plan.* Describe how to respond if the problem behaviors do occur (e.g., give Marty 15 minutes to calm down and return to a state of equilibrium, then provide an explicit reminder of how he can get help with his work; give explicit directions regarding how to correct work for Sandra).

Each person who interacts with the employee with ASD needs a script for any part of the plan that he or she expects to implement, so there is consistency across people and environments.

Designing the IPE

If individuals with ASD are eligible for VR services, the VR counselor will work with them or with their representative to choose an employment outcome, the particular VR services that will help to achieve the outcome, the service providers, and, if needed, the extended services required for supported employment as well as any postemployment services. Services may include the following:

- Transition services for students to help make the transition from school to work
- Counseling/guidance/career exploration
- Employment training activities
- Ongoing supported employment through job coaching
- Medical/psychological treatment
- Training/education
- Assistive technology
- Job search and job placement
- Employer education
- On-the-job training
- On-the-job natural supports
- Maintenance for additional costs that result from participating in a VR plan
- Rehabilitation technology, including augmentative communication and other assistive devices and aids
- Transportation for other services needed to achieve an employment outcome
- Follow up on job placement

Job Matching and Job Crafting

Considering the potential obstacles to employment for individuals with ASD, it will be important for the VR counselor to conduct a thorough assessment of potential job sites in order to match the requirements of the job to the specific skills, abilities, and interests of the prospective employee (Mawhood & Howlin, 1999). In

Chapter 3

addition, the VR counselor should consider the physical and social environment of the workplace, the flexibility offered by the employer compared with the needs of the individual, and the complexity of the job tasks.

A creative counselor can also consider crafting a job or helping the person to develop a micro business. Individuals with ASD may want to work from home, may want to work part-time, may have a talent and interest that is marketable directly to a consumer base, or may have the skills and desire to perform some of the tasks in a job, but not all. In these cases, the VR counselor may be able to create a job out of one already in the workplace or create a new one that is particularly suitable just for this individual. For assistance, many states have small business associations and other sources of assistance in becoming an entrepreneur, crafting innovative jobs, or opening up a micro business.

Job skills and interests. Studies of the traits of adults with autism and average intelligence have found a link between the characteristics of autism and professions in the sciences, namely mathematicians, computer scientists, engineers, and physicists (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubely, 2001; Baron-Cohen, Richler, Bisarya, Gurnathan, & Wheelwright, 2003). Other professions that use similar skills are musicians, architects, electricians, bankers, plumbers, toolmakers, lawyers, and programmers. Considering the particular interests of an individual (e.g., cars, geography, art), the particular skills and strengths of the individual, any unique preferences or needs (e.g., aversion to dirt, love of animals), the VR counselor is charged with the task of finding a match with the jobs available in the individual's community. Most often, a person with ASD will be able to learn the tasks and job skills if the job holds interest and is a match for their strengths. What will be more challenging are the "soft skill" requirements: adaptability to the setting and interpersonal interaction skills.

Support needs. As the VR counselor assesses the appropriateness of various jobs, considerations of the physical and social environment are just as important as matching the task requirements to the potential employee's skills and interests. In

Appendix D, the characteristics that might be presented by a person with ASD are matched with supportive job site characteristics and some accommodations that might be put in place through the IPE. A flexible job may include flexible hours, the opportunity to work at home, adjustments to the amount of work that needs to be completed in a given time, or breaks. In most cases a person with ASD will need a structured environment and a predictable routine. *It is critical that the VR counselor understand that autism is not a “fixable” condition but rather a lifelong disability, needing lifelong supports.* Part of the plan may also address supports for the “supporters,” especially if they will be supporting a person with challenging behavior (Pitonyak, 2005).

Structured environment. A job site that is organized to have limited distractions minimizes confusion and is comfortable for a person who has difficulty attending to more than one thing at a time. Additional structure may be needed and can be added through accommodations to the physical environment, the social environment, or the task requirements. These accommodations might include

- A specific person (supervisor, coworker, mentor) who can provide one-on-one assistance
- Prompts or cues to perform the job tasks (written word, color code, picture cues, etc.)
- Assistance with time management (time is invisible; physical clocks and timers are helpful if time must be estimated to start, stop, or interrupt a task)
- Alternative choices for behavior when the person gets anxious or encounters a problem
- Redesign of the physical space to remove unnecessary distracters

Predictable routine. Although many people thrive on familiar routines in their lives, routines can be a critical job feature for a person with autism, when changes (especially unexpected ones) may raise anxiety and stress. Studies of young children with autism have shown that when information is presented in a predictable manner, they are more socially responsive and attentive; when the

Chapter 3

same information is presented in an unpredictable way, their behavior becomes severely disruptive (e.g., Dawson & Lewy, 1989). As an adult, the person with ASD may be able to attend more easily to his or her job requirements and may be able to interact more appropriately if there is some certainty about the daily schedule and expectations. If the person with ASD does not know how to effectively and appropriately request help or ask questions (such as “What is that new desk doing in the hallway?” or “What do I do when I run out of paper?”), he or she may become anxious and behave in ways that are unusual or ritualistic. To assist the person with ASD, other adults in the work environment could explain in advance when the physical environment or routine will be different and encourage the person through transitions from one activity to another.

Designing Accommodations and Supports: Evidence-Based Strategies

The specific employment outcome might be full- or part-time work, in a large company or in a small business or at home, and may be with many or no coworkers. The employer will need to understand the accommodations that are needed and additional supports that will make the employee successful. Initially, the employee will probably need supported employment services with the assistance of a job coach. It is important to note that these services are limited to 18 months *unless under special circumstances the person with ASD and the VR counselor agree to extend the time in order to achieve the employment outcome identified in the IPE*. It is very likely that a person with ASD will need extended services, either through a VR agency or another supported employment service provider. When possible, coworkers or the supervisor may assume some of the “coaching.” But even when the employee acquires all of the job skills, it is the day-to-day challenge of interacting with others appropriately and managing the stresses associated with the characteristics of autism that will require ongoing support.

For children with ASD, there is consensus that “effective” programs have certain key elements. To extrapolate these elements to adult services, key features are individualized planning, an

emphasis on social skills development, planning for transitions (in activities, settings, people, etc.), systematic instruction, the involvement of family members in planning and providing services, a functional approach to problem behavior, and the provision of structured and highly supportive environments (Dawson & Osterling, 1997; National Research Council, 2001; Simpson, 2005). Within programs that have these components, a variety of specific strategies can be implemented to teach skills, prevent problem behaviors, and design supports to address the needs of the person with ASD.

An evidence-based practice is a specifically defined strategy that has a base of high-quality research over a range of different individuals that, when applied, results in specific behavioral changes (Dunst, Trivette, & Cutspec, 2002). Practices may have different levels of evidence, based on the extent to which they have been subject to rigorous research. Because a practice has not been thoroughly researched does not mean that it necessarily is ineffective; there is simply a lack of evidence to come to scientific conclusions.

Most research on the effectiveness of interventions with people who have ASD has been conducted on children. Very few studies have evaluated the effects of interventions or service models with adults. To design the services for an adult with ASD in an employment setting, the VR counselor will need to become familiar with a variety of instruction and intervention strategies and, if recommending them, needs to make sure they can and will be used with fidelity. It will do the person with ASD little good if a wonderfully effective strategy cannot be implemented consistently or if the people implementing the strategy do not use it correctly. With the help of the family and others who know the person well, the counselor will know how to match specific strategies with the characteristics and needs presented by the individual with ASD, design supports to prevent or minimize the likelihood of problems, and develop strategies to teach the skills needed for employment success.

Research indicates that the majority of strategies with evidence of success are based on behavioral principles. Teaching methods, such as shaping, prompting, and positive reinforcement, have been

Chapter 3

well researched with people who have autism and other developmental disabilities over the last 30 years. In addition to systematic instruction and positive behavior supports, the following are considered to be scientifically based and/or promising strategies:

Teaching language and communication. For example, *Picture Exchange Communication System* (PECS) is an augmentative communication program designed for individuals who lack expressive language (Frost & Bondy, 1994). While there are few high-quality research studies on its efficacy, numerous articles and anecdotal reports indicate that it can be a successful method to foster communication and develop language. Another example is *incidental teaching*, which involves providing instruction within the context of everyday activities around individual preferences. It has been studied most in relation to teaching specific language skills (McGee, Almeida, Sulzer-Azeroff, & Feldman, 1992; Elliott, Hall, & Soper, 1991).

Teaching social skills and self-management strategies. There are other strategies that focus on teaching individuals with ASD how to monitor and manage their own behavior. Called “cognitive” interventions, these strategies are generally used to increase appropriate social behavior and respond in potentially stressful situations. *Scripts*, for example, have been successfully used to teach persons with ASD how to behave, make requests, and respond in social situations and various environments. Modeling and videotaped scenarios have been used to teach different skills, ranging from altering tantrum behavior to grocery shopping skills and engaging in conversation (Ayres & Langone, 2005). Same-age peers have also been successfully taught to use scripts to interact with young people with autism; in the work setting, coworkers could be given possible scenarios with examples of how to respond to and include the person with ASD. *Social stories* are another promising way to teach a variety of behaviors (Gray, 1996). The important social cues and appropriate responses in a potentially challenging situation are described with four components: *descriptive* sentences that provide information about the setting, subjects, and actions that will occur; *directive* statements about how the individual should respond in that situation; *perspective*

sentences that describe the possible feelings of the individual and others and how others may react in the situation; and *affirmative* statements that describe shared beliefs of a given culture. Additional *control* sentences that use analogies to promote understanding of the situation and *cooperative* sentences that identify who is available to help and how that help will be provided may be included (Gray, 2000). By reviewing and rehearsing these stories prior to an event, the individual with ASD may be more likely to respond appropriately and with less anxiety.

When planning to select and design intervention and support strategies, the VR counselor can ask:

- What is the outcome that I expect as a result of this strategy?
- What does the research say about its effectiveness?
- What are the potential risks of using this method?
- Can this strategy be reliably implemented in the employment setting?
- How will we evaluate whether or not the method works?

Service providers should design their instruction or intervention methods carefully and gather data on individual performance and progress so that the strategy chosen can be evaluated for its effectiveness with that individual.

What the Employer Can Do

Most employers provide workplace accommodations for individuals with disabilities. The IPE will need to define the appropriate level and specific type of support that will lead to job maintenance. Job supports may very well go beyond job skills training and assistance with job routines. The development of specific social skills and on-the-job social supports will be important to promote acceptance by coworkers and successful participation in the culture of the work environment. The employer's management and supervision style, flexibility, and willingness to provide the necessary accommodations are important factors for the success of persons with autism in the workplace (Unger, 1999). Employees with ASD will be successful

Chapter 3

and satisfied in work settings that do the following (Hagner & Cooney, 2005; Hurlbutt & Chalmers, 2004):

- Provide a consistent schedule and job responsibilities
- Clearly describe the job duties, responsibilities, expectations, and rules ahead of time in terms of productivity, breaks, tasks, and social interactions
- Keep social demands manageable and predictable
- Provide organizers to structure the job and keep track of work
- Reduce idle or unstructured time
- Provide extra time before the start of work to get organized
- Communicate directly and specifically
- Verify that communications are understood
- Provide reminders and reassurances
- Provide specific directions for how to ask for help
- Encourage coworkers to initiate interactions and help to “keep an eye out” for the employee
- Provide a familiar person until the employee and company staff get to know one another
- Provide ongoing job mentorship
- Transfer service provider relationships and supports to company employees

Finally, employers should know that there are many advantages to hiring a person with ASD. They are more likely to arrive at work on time, will rarely miss work due to illness, and will not waste time chatting with coworkers, making personal phone calls, or engaging in personal time on the Internet. If provided with structure, routines, clear assignments, and accommodations for the unique characteristics that their autism presents, employment can become a reality and a successful experience for both the person with ASD and the employer.

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Chapter 3

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APPENDIX D

FINDING A JOB AND DESIGNING ACCOMMODATIONS

When looking for a job for the individual with ASD, it is always important to capitalize on his or her strengths and interests, while looking out for situations that may not offer the physical and social environment that will lead to the employee's success.

If a person . . .	Match with a job that . . .	Consider accommodations such as . . .
<p>Uses a nonverbal communication system or has limited verbal skills and has limited understanding of social behavior (e.g., facial expression)</p>	<p>Requires limited communication with the public</p> <p>Has an employer and coworkers who will make the effort to learn</p> <ul style="list-style-type: none"> • The person's alternative way(s) of communicating • How the person may respond to abstract verbal phrases and interpersonal interactions 	<p>A communication device programmed with words or symbols that are appropriate to the person's skills/needs and are commonly used on the job</p> <p>Teach coworkers:</p> <ul style="list-style-type: none"> • How the alternative or augmentative communication system works • How they may be interpreted when interacting with the person <p>Teach the person specific social skills that will aid in job performance and interactions with coworkers</p>
<p>Talks passionately about a favorite subject (e.g., birth dates, the Internet, comics) without changing the subject when appropriate</p>	<p>Has opportunities for social interaction in breaks</p> <p>Is related to the person's favorite subject (e.g., office assistant who has employee birthday cards as part of his assignment; web-based research; retail in a book or children's store)</p>	<p>Teach the employee how to check with others about his or her continued interest in the subject (e.g., Can I tell you more/ask you more?)</p> <p>Establish cues that coworkers can use to request a subject change or signal a limited time left for discussing the subject</p> <p>Establish clear and predictable opportunities for discussing favorite subjects within a specified time frame</p>

If a person . . .	Match with a job that . . .	Consider accommodations such as . . .
Is sensitive to particular sensory stimulation	Does not have that particular sensory stimuli in the physical environment Can eliminate the source of stressful or distracting sensory input	Depending on the sensory sensitivity: <ul style="list-style-type: none"> • Alter the type (e.g., fluorescent bulbs) or brightness of lighting • Provide ear plugs • Organize the physical work space so that it is clear and uncluttered • Adjust the temperature • Modify printed materials to reduce visual distractions by removing unnecessary information • Speak very clearly and wait • Do <i>not</i> insist on eye contact
Becomes anxious in certain situations (that are identified in the interview and assessment)	Has limited opportunity for the particular situations that may result in anxiety Has opportunities to take a break from anxiety-producing situations	An object to manipulate (e.g., soft ball to squeeze, pennies to rub) or another action that the person can learn to use when anxiety begins to rise Opportunities for a break from the situation leading to anxiety as well as a strategy to change the situation so the employee can return to work A mentor (job coach, coworker, supervisor, etc.) who will assist the employee in managing the environmental or interpersonal situation
Has difficulties making transitions from one activity to another (i.e., becomes anxious making the transition, refuses to stop doing one thing, or insists on completing an activity even when it is time to stop)	Has a daily routine and is predictable Does not require many changes in routine	A timer to give advance notice of transition (e.g., set off 5 minutes before transition and accompany with encouraging verbal reminder) A social story that describes the transition situation and how to act (review and rehearse) Advance notice of any changes to the schedule and rehearsal of the new/different activity/ situation prior to that event

Chapter 3

If a person . . .	Match with a job that . . .	Consider accommodations such as . . .
Engages in ritualistic or self-stimulatory behavior (e.g., rocking, shaking hands, rolling a string between fingers, etc.)	Would not have a problem with odd or different behavior	Possibly none! A quiet place to go (if needed) Explanation to supervisor and coworkers about the purpose that the behavior serves for the person (if known) and how to respond (if at all)
Does not make accurate judgments about safety	Has no equipment or settings that pose a physical risk	Very explicit and clear information about what is and is not safe
Has difficulty processing auditory (verbal) information	Involves tasks that are more visual in nature and don't require a lot of verbal interactions	Visual schedule (pictures, symbols, written words, as appropriate for the person) Visual cues (e.g., color code, symbols, written directions) Very clear and direct verbal information (directions, explanations, questions, etc.) Waiting, once a question has been asked or a direction has been given, to allow the person time to process and respond (don't keep repeating the question or direction)

Chapter 4

SUPPORTING SUCCESSFUL EMPLOYMENT

By Thomas Duffy, Robert Oppermann, Michael R. Smith, and Stephen Shore

This chapter explores some factors that vocational rehabilitation (VR) counselors should be aware of when developing supports for an individual with autism spectrum disorder (ASD), to help that individual not only secure employment but to maintain that employment and ultimately develop a career. This chapter reflects four points of view: those of a state VR administrator, a practitioner at a community rehabilitation program that serves individuals with ASD, an educator on the autism spectrum, and a trainer at a university-based continuing education program.

Given that people with ASD exhibit such a wide range of skills, abilities, interests, and deficits, it is vital that the supports designed to help such individuals acquire and maintain employment be customized to meet their unique needs. These supports can range from informal assistance provided by a coworker to a very structured environment where the individual is closely supervised. Because ASD is a pervasive developmental disorder, supports are often needed for the long term or even the life span. That does not mean that someone who is on the autism spectrum can't be a productive employee and a valued member of society.

In this chapter, we build upon the discussions in previous chapters on transition and accessing the VR system. Several important

Chapter 4

themes have been identified that should be considered by VR counselors when they are setting up supports for people with ASD in a vocational setting. Five themes are discussed in this chapter:

- Relationships with employers
- Communication strategies for employment success
- Workplace accommodations
- Self-advocacy skills
- Strategies to “support the supports”

Relationships with Employers

The relationship between the employer and the employee with ASD is critical to the vocational success of the individual with ASD. This section reviews the VR process discussed in chapter 3 and ties key points into establishing and maintaining an effective relationship with an employer.

Planning for employment may begin with a thorough evaluation of the individual. Once the evaluation is complete, job matching can take place. Job matching answers the question: Which type of job is appropriate? The next step is taking this general vocational objective and considering it in a specific setting. If, for instance, the vocational objective is to become a printer, then businesses with printing opportunities must be located. The way in which a specific print shop operates has to be analyzed. A job analysis will break down each task necessary for success. After the job analysis, an environmental analysis is necessary. Then the education of supervisors and coworkers should be considered. All these processes will be discussed in further detail. They are necessary for employment success. However, this effort will not result in success unless an employer is willing to accept the challenge.

Developing job placement opportunities requires planning. Research a company, not only to discover the nature of its business but also to find out the key person to meet. Depending upon the size and structure of the business, the key person could be the owner, a human resource director, or a department manager. Their time is important. Schedule a meeting at a mutually agreed-upon time. Be as accommodating as possible. Be prepared for your

meeting. Know what you wish to accomplish. Some employers have immediate needs and may want to move quickly. Some will be skeptical. Many will have limited knowledge or misinformation about ASD. Still others may have no interest at all. The VR counselor should be prepared for each contingency.

The responsibility of the VR counselor is to balance the needs of the employee and the needs of the employer. If the employer needs are not met, a placement may take place but will not last. Develop a strong partnership with the employer. Listen and respond accordingly.

Do not overpromise. Success will often lead to other job placement opportunities. Every time a person with autism is successfully employed, it can benefit the next person looking for employment. The employer of a successful ASD employee will be more inclined to give someone else an opportunity and may give a testimonial to other employers.

Creating a pool of employers for placement opportunities requires relationship building. When trust is achieved, the relationship can grow. Trust can be developed by fulfilling promises, being available when needed, and having successful outcomes. Patience and perseverance will also be required. Strong relationships take time to develop. They are well worth the effort. Without these partnerships, employment will remain out of reach for most people with autism.

Understanding an employer's mission is critical. Whether providing a service or creating a product, businesses need to do so in a productive and profitable manner. A business needs employees to help accomplish its goals. Whether a person has a disability or not, whether that disability is ASD or not, as long as a person can help a business be successful, that opportunity should be available. It is the responsibility of the VR counselor to develop partnerships and nurture them, so employers will give people with ASD opportunities in the workplace.

Education of Employees and Staff

It is important that the supervisor and other employees receive education regarding ASD generally and how ASD applies to the

Chapter 4

individual employee specifically. An understanding as to *what* the employee with ASD needs regarding communication, sensory accommodations, and structure, as well as *why* these issues are important for the employee, helps the employer better understand the person with ASD. This information also increases the chance that the employer will be supportive of the new employee once the “mystery” about ASD is gone. The employer now can help educate other staff regarding these issues.

There are several ways to provide this information to employers. Often, the individual with ASD wants to make a presentation to his or her workgroup (National Autistic Society, 2004). Some organizations prefer to have the information provided by a human resources professional or the VR counselor. Others would like to have key members of the organization (e.g., the employee with ASD’s immediate supervisor or team members) receive formal training, with them disseminating the information as needed to other employees. The job coach can certainly provide ongoing education to the employer as issues arise on the job. However the information is presented, one must not forget to point out the advantages of having this employee with ASD in the workgroup by emphasizing the skills and abilities that this employee brings to the workplace (National Autistic Society, 2004).

Communication Strategies for Employment Success

Once the person with autism has entered the VR system and the job search has begun, our work is really just beginning. The path to successful employment may not be a straight line to a perfect job. Instead it may be a winding road, with alternating success and failure. As described earlier, adults with autism will probably require supports throughout their lifetime. Supports may be provided by an agency specializing in autism, or they may be informal. In some cases the VR counselor may team up with the person’s family, friends, and possibly the employer to form an informal “support team” for the person.

With so many people and agencies involved, communication becomes a critical support strategy in two ways. First, the person’s own communication ability will influence his or her potential for

independence and success on the job. Second, the VR counselor must ensure that an effective communication “system” develops around the person. The system includes and links the different people, agencies, and employer to each other and to the person. Developing an effective communication system in the workplace is a delicate balancing act. The person with autism has unique needs, but so do most employers. Properly balancing the needs of the employer and the person can be a challenge, one that every successful job coach has met at one time or another.

Communication and Self-Direction

For many young people with ASD, it can be exciting to enter the world of employment. Outside the structure and limits of traditional schools, there are many opportunities for the person to learn how to communicate toward the goal of self-direction. From expressing job preferences during the vocational assessment to selecting potential employers during the job search, opportunities to communicate and to become more independent abound.

For the typical young person, communicating and making choices at work quickly becomes routine. Although the process for the person with autism will be different, the outcome will hopefully be the same. All workers must learn to communicate to get their needs met, while at the same time learning to manage frustration when communication does not work. The development of communication and self-control skills increases confidence, independence, and the intrinsic motivation that is so essential to work success. This is such an exciting journey—not only for the person but also for those of us who comprise the support team!

Making Communication a Priority

For many adults with ASD, successful employment is more a long-term endeavor than a one-time event. For example, people now have an average of more than 10 jobs in their lifetime; the person with autism may have twice that number. VR counselors should understand that for the person with autism, change is to be expected, planned for, and managed.

It is difficult if not impossible to list a top ten “steps to employment success” for the person with ASD. ASD is complex,

Chapter 4

and the impact it has on each individual is unpredictable. Combined with the fact that every job has different expectations and informal rules, we must avoid recommendations or strategies that are overly prescriptive. Instead, we should look at successful employment outcomes. Throughout all of these success stories, one will find a connecting theme: Good communication is key!

The good news is that communication skills can be learned. We view communication skills as learned behaviors, and like so many learned behaviors, communication can be predicted by the rules of reinforcement. If communication on the job works to the person's benefit (i.e., if communication is reinforced), the behavior of communication will increase. If communication does not work for the benefit of the person (i.e., communication is not reinforced), the behavior will decrease.

Over the years, behavioral approaches were considered effective in the treatment and education of people with ASD. The term "behavioral" can mislead people, probably because of our cultural view that behavior must be bad if we are talking about it. Many people with ASD have unfortunately become defined by their negative behavior. The emergence of positive behavioral support approaches leads to a different perspective. Positive support strategies recognize the capacities of each person and the development of support plans that emphasize the person as a lifelong learner. Instead of treatment strategies with the primary goal of eliminating behavior, (i.e., "stop doing this"), positive strategies can be illustrated by the phrase, "I will assist you to learn this."

Communication on the Job—A Skill to be Learned

Many employment failures of people with ASD have been attributed in the past to the person having a "behavior problem." In reality, the behavior problem may have been better described by the old movie line, "We have a failure to communicate." The VR counselor and the support team should learn how to respond to the person's communication with tangible action. The challenge for the VR counselor may be one of setting priorities. To respond to every comment or request of the person will be impossible. However, an expression of vocational interest provides a natural

opportunity for reinforcement. For example, if the person indicates an interest in a particular job such as being a cook, the counselor can simply respond, “That sounds like it might be a nice job. I’m glad you told me!” Immediate reinforcement of communication is recommended even if this may not be the best job for the person. Hopefully, you will “prime the pump,” reinforcing the start of a productive relationship in which the person will talk about his or her preferences and dislikes regularly. More tangible (long-term) reinforcement such as contacting a restaurant owner regarding potential jobs can come later.

“A Career Is a Series of Jobs—A Job Is a Series of Tasks—A Task Is a Series of Behaviors”

If the expression of a vocational preference seems unrealistic, there will be many opportunities for the goal to be “shaped” to one that is more realistic. The process of breaking broad career goals into smaller, more specific goals will afford additional opportunities for communication and reinforcement. Take the example of a person who indicates an initial interest in a career in computers. The VR counselor might suggest that the person try three or four different jobs related to computers and give the person an assignment to communicate preferences and dislikes at the end of the trial.

Possibly, the first job trial might be data entry on a computer. Instead of asking the person a very broad question, “Do you want a computer job?” or “Do you like data entry jobs?” we recommend asking the person to identify preferred and nonpreferred tasks *within* the data entry job trial. For example, the person might like using a computer but dislike sitting for most of the day (one preferred task and one nonpreferred). Because the person was prompted (taught) to communicate on very specific aspects of the job, reinforcement can be provided in a very tangible way. The counselor can help the person move toward a job that reflects his or her interests, such as suggesting a shipping job in a computer warehouse. There the person gets to do preferred tasks (using a computer to process orders) and can also move throughout the warehouse. Simply put, the more effective the communication, the greater the chance the person will end up with a good job match.

Chapter 4

Let's take it a step further. Consider that many people with ASD have significant challenges or that there may not be a warehouse available for a job trial. The counselor could still facilitate the process and “prime the pump” of effective communication and self-direction. Warehouse jobs are typically a series of tasks that might include pushing a hand truck or using a taping gun. The person might be prompted to sample such tasks in a work program or school. If the person is asked which task he or she likes, and the support team responds in some way, the process is off to a good start. A person who learns communication skills, whether it be in a vocational program or on the job, will have a much better chance of employment success. It is critical that the person be engaged actively and that there is a communication system that works.

Systematic Job Trials, Proactive Communication, and a Different Way of Meeting

We sometimes think that the first job for young people with ASD will be the last job (and the best job!) they will ever have. This is understandable because jobs for people with ASD can be hard to find, and there is usually so much excitement over the first job. However, it makes sense to keep in mind the number of jobs these people may have over their careers. They will probably move to a different job at some point, and we may consider the first job, in retrospect, a “work trial.” The systematic accumulation of information about the individuals' job experience, including their abilities and preferences, is, in some ways, more important than success at the first job.

Systematic job sampling makes sense because it offers the person the opportunity to identify preferences from an array of different experiences. A job may look like a good job only when experienced in comparison to a bad job. In systematic job sampling, there is a *planned time* to begin and end each work trial, and there is also a *planned time* for the person to report on the experience. These planned times may be called a “meeting,” but the form of the meeting will be as different as is each person with ASD. A meeting can be formal, one time a week in a conference room, or very informal, conducted at the person's work station several times a day for a few minutes each time. If the person is

verbal, the meeting will include conversation and typical interaction. If the person is nonverbal, the meeting could include pictures, symbols, and/or audiovisual tools.

The purpose of the meeting is to proactively engage the person before he or she has a concern that builds and leads to a problem; to facilitate communication so the person can learn how to identify and solve problems; or simply to express a preference or dislike. Having scheduled meetings (remember, we use the term “scheduled” loosely) conveys the message that the person should learn and use self-control. Many people with autism struggle with anxiety and impulse control. Many have learned negative behaviors as a way to control their environment. Yelling, hitting someone, or throwing something typically leads to immediate attention and the resolution of whatever was bothering them. Instead of this reactive strategy, we recommend the person learn self-control, including the ability to wait patiently for problems to be resolved. There must be an environment that balances the needs of the person and the employer. The person needs assurance and a mechanism to address his or her needs on the job; the employer needs to have employees who are committed to the completion of tasks and who possess the requisite degree of self-control and effective communication.

Example #1—Tom

Tom is an adult with autism who often becomes stressed when trying new activities, particularly vocational activities. He prefers not to try new things, and he is often impulsive. Tom was asked by a vocational supervisor to do a job trial recycling paper, cans, and bottles at a nearby college. Tom had previously sampled and enjoyed a job on a window-washing crew. While Tom enjoyed window washing, he had also expressed some interest in the recycling job (or at least taking the ride up to the college). In short, Tom was unclear as to his vocational preference, as was his support team.

In consideration of his work history, impulsiveness, and communication challenges, Tom was asked to do a 3-day recycling job trial by his vocational supervisor. Tom

Chapter 4

was told he would meet with his supervisor after 3 days of the job trial. (Tom required a very clear definition, such as “go to the job three times,” as opposed to vague definitions such as work “for about a week.”)

Tom was asked to wait to make any final decisions about his preferred job until the completion of his job trial. Tom did the recycling job trial on Monday, Wednesday, and Friday. On Friday afternoon, he met with his supervisor. His supervisor prompted Tom to give information about specific preferences and dislikes. Tom said that he liked riding in the pick-up truck that carried the cans and bottles but that he disliked getting dirty. Tom requested to work as a regular member of the window-washing crew and to never do the college recycling job again. The experience was valuable to Tom in many ways. He learned the challenges and benefits of trying different things, of participating in a meeting to have his needs met, and of utilizing self-control while doing nonpreferred things such as riding in a dirty truck. Tom was rewarded with a job that he preferred and has held now for approximately 11 years.

Asking questions that compare one work experience to another is helpful because there is a point of comparison. Another strategy is to ask specific, close-ended questions. Questions that lead to specific outcomes are also recommended. “Do you want to collect the bottles or should I do that?” is a clear question that should lead to a clear outcome. Close-ended, action-oriented questions can provide information while helping the person develop a sense of control through communication. The question, “Do you like this job?” may appear to be a clear question leading to a yes or no answer. In reality, this question can be difficult to answer for the person with autism. He may give the answer that he thinks the counselor wants to hear. A better way to collect reliable information is to collect information about specific tasks and activities systematically over an extended period of time.

Example #2—George

George, a person who had relatively advanced communication skills, was starting a new job at an auto

parts store. George was excited but nervous about this new endeavor. Halfway through his first day, George wanted to quit the job. Quitting probably appeared to be the quickest and easiest way to reduce his level of anxiety and discomfort. George was encouraged by his job coach to wait until the end of his shift for a “meeting.” George was told that the reason for the meeting was to talk about what he liked and disliked about this new job. George was then prompted to use relaxation skills he had previously learned. During the meeting at the end of the day, George indicated that he liked shelving items but disliked sweeping the sidewalk outside the store. George was reinforced in several ways for meeting with his job coach at the end of the day. He was praised for using relaxation techniques to manage his anxiety during the day. He felt important because the job coach met with him in a small conference room commonly used for management meetings at the store. He was then reinforced further when the job coach spoke to the manager of the store to negotiate a trade of duties. George’s duties were changed to include more shelving and less sweeping. George learned that having self-control, good communication, and a planned time to meet could “work” for him.

Communication Strategies for Individuals Who Are Nonverbal

Communication can be verbal for some individuals with ASD but will occur differently for others who do not have verbal skills. Once again, a successful outcome for the person is critical (communication must “work”!). Communication can be gestural or facilitated through the use of assistive devices (hand-held computers, pictures, etc.). Communication can often occur based on the observation of a staff member who knows the person well. This is fairly common in the world of ASD, as many job coaches have that undefinable critical “it,” the ability to understand ASD and behavior.

A job coach who checks in informally throughout the day can become a prompt for communication. Simply seeing the job coach approaching can lead to a series of nonverbal but critically

Chapter 4

important “signs.” The person may smile, frown, stop working, nod his head, or simply stand up to let the job coach know something is right or wrong. If the worker reports to the job coach that things are going well, the job coach can reinforce the absence of a problem. “Hey, you are a terrific worker.”

Example #3—Kyle

Kyle is a person with limited communication abilities and some history of aggressive behavior. A job coach was observing Kyle working in the mail room. The job coach, a very skilled observer who had “it” (see last paragraph), noted that Kyle enjoyed most aspects of the job but struggled when sealing the envelopes. At the end of the first hour on the job, Kyle’s job coach said to him, “It looks like sealing the envelopes is hard.” When Kyle nodded in agreement, the job coach replied, “Thanks for letting me know. Tomorrow, I will assign someone else to do it.” This is a simple example of a proactive communication support strategy for a nonverbal person. The form of the communication and the scheduling of the meeting matter less than that the communication works for the person.

Workplace Accommodations

A Common Tale Told in Introductory Accounting Classes

A fellow worked for 40 years as an accountant. Every day before starting, he would look into the top drawer in his desk, nod his head, and begin his work. He was very successful and never made a mistake. There was much curiosity and discussion among his coworkers as to what he was doing. After he retired, his colleagues could bear their curiosity no longer. Opening the drawer they found an old, yellowed sheet of paper with the words “Debits on the left and credits on the right.” Although this tale is probably an urban legend, it does bring up a point. This experienced and successful accountant needed a written accommodation to make sure he did his job correctly.

We all need some type of accommodation to perform our respective jobs to the best of our abilities. So does a person with

ASD, just to a greater and often more formal degree. Several accommodations can create an environment that is conducive to the success of a person with ASD in the workplace: a mentor (career and/or social), a job coach, the job structure, environmental/sensory accommodations, and social skills. Each of these is discussed below.

Mentor (Career and/or Social)

Persons with ASD have a tendency to feel overwhelmed with sensory stimuli that are beyond their control and are often confused by social relationships for which they do not know the rules. A mentor can help reduce stress by being someone whom the employee can talk with if social factors become confusing or overwhelming. The person chosen to be a mentor should be viewed as a wise and trusted advisor and role model. A good choice for a mentor would be an employee who has interests similar to those of the person with ASD. This ensures a common ground. A mentor is important because he or she can teach social mores, help the individual learn conformity to rules, and help the individual develop diplomacy and tact, which can be so very difficult for the person with ASD. A careful review of the workplace may identify coworkers who could naturally and comfortably fit the role of a social coach or mentor.

How many of us have sat through a staff meeting and immediately afterwards sought out a trusted colleague to process what went on? What did this person mean by this comment or this suggestion? Did you hear what I heard? Most people have a trusted colleague at work to discuss office politics, agency/departmental issues, and other work-related concerns. For a person with ASD, this concept could be formalized (at least initially), perhaps using a job coach in the role of social coach/mentor if a colleague was not available.

Example #4—Mark

Mark works as an accountant in a mid-sized accounting firm, and he identifies himself as having Asperger's syndrome. There is a lot of office humor, some that Mark has difficulty interpreting. A coworker, Bill, has recognized that Mark sometimes struggles with understanding the

Chapter 4

humor and/or his coworkers' intentions. When Mark struggles with these social interactions, his work performance usually suffers, as his concentration on his work tasks is competing with processing the social interaction. Bill seeks Mark out to process the interactions and also makes himself available when Mark realizes that he needs some assistance figuring out a social situation with his colleagues.

A career mentor could expand upon the concept of social mentor or coach. Effective mentoring is an important component of job retention and career development. A mentor who not only helps interpret confusing social situations but also helps a person with ASD better understand the “big picture” and what is expected and important for success could be invaluable.

Job Coach

A second accommodation that might be utilized for this population is a job coach. The job coach can fulfill a very important support role for employees with ASD. He or she can not only teach the job skills necessary to perform the job, but also help individuals with ASD by analyzing the unique “culture” of the workplace and identifying the social competencies that would be most helpful for them to acquire. The coach can assist these individuals in understanding and handling the nuances of routine workplace social interactions and work-related communications (Muller, Schuler, Burton, & Yates, n.d.). Social cues are difficult for individuals with ASD and may be practiced with the help of a job coach or mentor. Situations can be scripted and rehearsed to teach skills that may help the ASD employee interact with colleagues at work (Fast, 2004). Facial expressions and body language should be observed in relation to the situation. The job coach can also serve as a translator between the individual and the supervisor, especially in the early stages of employment, and can be very important to the transition.

The job coach is uniquely in tune with the communication needs, stress management system, and learning style of the person with ASD. Helping a person with ASD develop effective self-advocacy

skills is critical, so that the formal services can fade and natural supports can be used. The job coach not only helps the employee navigate the social part of the job as described above, but also ensures that the necessary structure is present on the job.

Job Structure

Structure for a person with ASD is like a wheelchair for someone with a spinal cord injury or Braille for someone who is blind. Structure or the prosthetic environment is key to vocational success for an employee with ASD. Understanding and having some input in the development of the structure of the job enables an individual with ASD to feel a sense of control, thereby helping the person focus on the task at hand and be open to learning new tasks. Structuring the job is also important when teaching the individual with autism to perform the tasks associated with the job. In training an ASD employee, it may be helpful to break a large task into smaller steps. Verbal instructions should be followed by written instructions, to which the employee can refer if and when he needs it. Repetition may prove beneficial. Job coaches and supervisors should remember that information processing may be a problem in a multistep process. Adequate time should be allowed for the employee to process and memorize each step of the process (Fast, 2004). Many people with ASD are visual learners and must have everything demonstrated to them. Other people with ASD are auditory learners and will need to have everything explained to them. A good understanding of the employee's learning style is very important for everyone involved. Instructions should be concrete (Fast, 2004). Feedback is important, so provide reminders and suggestions for improvement on a regular basis (Hagner, 2005). When changes in tasks or personnel become necessary, explain the changes and reassure the individual that everything is okay (Hagner, 2005).

Environmental/Sensory Accommodations

Individuals on the autism spectrum often have difficulty with the environment. This is especially true of auditory and visual factors that may be present in the workplace (Grandin & Duffy, 2004). As one might imagine, the workplace is full of sights and sounds, many of which are problematic to people with ASD. Being in a

Chapter 4

large office area where 15 people are talking all at once can create immense fear and anxiety. Persons on the spectrum cannot attend to one voice and tune out all the others at the same time; too much processing is required and too little processing capacity is available. Other sounds in the workplace can be problematic as well, such as phones ringing, file drawers closing, chairs squeaking, and machines operating. As a result, a quiet place to work is often a necessary accommodation for an employer to make when employing someone with ASD. Other accommodations could include the use of headphones or earplugs that serve to diminish the sounds that can be commonplace in the work environment. Sarah Banker (2003) suggests that the use of white noise sounds such as fountains or fans may assist with making the workplace more tolerable. Thus, several simple solutions are available for the problem of auditory overstimulation.

Individuals on the spectrum experience problems with some types of visual stimulation, such as fluorescent lighting and CRT-type computer monitors. Where fluorescent lighting is a problem, a simple solution may be using incandescent light bulbs or providing more natural light from windows or skylights (Grandin & Duffy, 2004). These actions reduce or eliminate the constant flickering that the individual experiences. As for CRT-type computer monitors, the flat panel monitors available today do not flicker in the same way and can be a simple solution to a common problem (Grandin & Duffy, 2004).

Another related issue can be what an individual is able to see visually from his or her desk. Being able to see too much from one's desk can cause overstimulation and result in a complete lack of concentration or distractibility. Simply making a desk face the wall can alleviate this problem for persons with ASD (Grandin & Duffy, 2004).

Often people with ASD report that these sensory sensitivities can be painful and exhausting (Stillman, 2003).

It is important to help individuals with ASD develop a sensory plan (what they need in their work environment). By developing their self-advocacy skills and calling on the support of the job

coach and VR counselor, individuals can interface with the employer so that the accommodations are understood and continued. Often the sensory accommodations are not elaborate and are relatively easy to implement.

Social Skill Development

Often people with ASD can perform the critical tasks of their job but have difficulty managing the social aspects of that job. These difficulties with the social component of the job may hinder their career development or even cause them to lose employment.

Interpreting social cues is difficult for many individuals with ASD. They often do not read facial expressions, tone of voice, or body language well. Many people with ASD take things literally and have difficulty with generalizations. Clear instructions or explanations are important in working with these individuals, so remember to be concise and specific (National Autistic Society, 2004). Eye contact is difficult because they are unable to listen, look, and concentrate. This lack of eye contact is often perceived as boredom, inattentiveness, or rudeness and can cause offense (Fast, 2004). It may be necessary to target with the individual the critical times that eye contact is needed on the job and work towards using it then, rather than having a global goal of maintaining eye contact during as many interactions as possible.

Interpersonal boundaries present difficulties. Due to their inability to perceive and understand nonverbal cues, combined with their literal mindset, many employees with ASD may fail to understand their boss's or colleague's expectations and intentions. They may never realize that they have crossed an invisible line and caused offense (Fast, 2004).

Social cues may be practiced with the help of a job coach or mentor, as mentioned previously. Situations can be scripted and rehearsed to teach skills that may help the employee with ASD interact with colleagues at work (Fast, 2004). Concepts such as small talk can be learned and developed. Equipped with a couple of ways to engage in small talk with coworkers and supervisors, the person with ASD can be more a part of the work team. This

Chapter 4

could make it more likely that a relationship will develop between team members and more likely that problems on the job can be more effectively dealt with. Facial expressions and body language should be observed in relation to the situation. The employee should practice conversation with appropriate facial expression, and the use of a video can be very helpful.

Jobs often have certain expectations, social or work-related, in addition to the specific job tasks. These expectations may not be understood by people with ASD if they haven't been explained to them. Explaining these unwritten "rules" can help the person avoid misunderstanding and fit in with their colleagues.

Breaks and lunchtimes may be difficult for these employees due to their lack of social skills. These individuals may also have trouble understanding joking or sarcasm (www.autism.org.uk). A mentor or job coach can facilitate conversation and help the employee learn to converse with others.

Many critical social interactions with supervisors and coworkers (those that directly impact upon job performance) can be identified during the job development stage. The individual can develop ways to effectively communicate in those critical social interactions with the assistance of a job coach initially and then hopefully more independently. The person with ASD may need prompts and other supports from others to interact successfully in a critical social situation on a long-term (or forever) basis. It is possible that these prompts and supports could come from the work environment eventually.

Self-Advocacy Skills

Appropriate Self-Advocacy in the Workplace

Self-advocacy involves knowing when and how to make one's needs known to another person in a way they can understand and comply with (Shore, 2004).

Effective self-advocacy skills can often be vital in a work setting. The clearer individuals can express their needs (e.g., sensory needs related to lighting and noise level or work tolerance issues such as

whether mini-breaks are helpful) or preferences (e.g., what tasks they enjoy), the more likely that those needs will be met. Those with autism are the expert in knowing what they need to be happy and successful at work; the challenge is for them to find an effective way to communicate those needs to the right people on the job. For people who are nonverbal or have limited verbal skills, it is up to them and those who support them to utilize what does work (e.g., picture exchange communication system) and to continue to use and develop those skills.

Example #5—Juan

Juan is a young man with autism who is nonverbal but communicates with a variety of noises and gestures. He successfully developed ways to communicate in a school and home setting. When it came time to transition to adult life, Juan was able to teach his support people and employers his language. Those who worked with Juan prior to transition emphasized his role as a self-advocate to help him meet his needs on the job.

The thought of having to develop accommodations for employees with disabilities can be a daunting task for many employers, possibly due to the lack of education on how to work with people having different needs. It is not realistic for an employer to become an expert on providing accommodations for people on the autism spectrum. For this reason, it behooves those supporting people with autism to teach skills in self-advocacy and disclosure. For example, a common characteristic of people with autism is sensitivity to fluorescent lights; they perceive such lights as most other people perceive a strobe light. That's fun for Halloween but not conducive to productivity in the workplace.

Persons with this sensitivity would be much better served if they could advocate for themselves by asking the supervisor for a change in lighting, recommending what that change could be (such as an incandescent lamp or seating closer to the window), and wrap up the self-advocacy efforts with a soft disclosure of having sensitive eyes. However, teaching skills in appropriate self-advocacy and disclosure is necessary since people on the autism spectrum need direct instruction in this area.

Chapter 4

Stress management techniques that help a person deal with changes in routine, sensory overload, and everyday job stressors are important to cultivate. If persons with ASD can let supervisors and coworkers know “what works” for them, they stand a greater chance of being understood by their colleagues. A job coach or VR counselor may need to help employees with ASD explain their stress management system. Some ways to deal with stress and to “self-soothe” (e.g., through rocking, hand flapping, hand biting, rote verbalizations, etc.) may or may not be effective in the workplace and may need to be tweaked or replaced with more effective strategies.

Sometimes you don’t know the extent to which persons will utilize their “self-soothing” techniques until they are on the job.

Example #6—Adam

Adam is a young man who flaps his hands very vigorously when anxious, stressed, or unsure how to communicate. (He has pretty effective verbal skills.) Over time he was able to work out with his support people other ways to communicate when he had questions about the task or needed more supplies, and he saved the hand flapping for when he was really stressed. Adam eventually was able to self-modulate his hand flapping in most work situations.

An additional facet of self-advocacy is disclosure, or stating the reason why accommodations are being requested. Disclosure can be risky because it deals with having to tell someone something potentially damaging to one’s reputation. Disclosure is more than merely saying “I have autism”; it is describing how autism impacts the relationship or situation.

Stephen Shore, a person on the autism spectrum, is a contributor to this document. He is the executive director of Autism Spectrum Disorder Consulting and is also an author, musician, and educator. He wrote about disclosure in different circumstances:

Had I been more aware of how my diagnosis of autism at age 2½ affected me as a busboy, I might have requested a change of duties to where there was less noise in an effort

of self-advocacy. Then I could have disclosed that I was sensitive to noise and the clamor of the restaurant floor interfered with my doing my work. Being on the autism spectrum would not have been mentioned, which brings up the concept of soft and hard disclosure. Dennis Debbaudt (2001) talks about hard versus soft disclosure when choosing to tell another person about being on the autism spectrum. . . .

Disclosure in the workplace is best done on a need-to-know basis. For example, I don't disclose my being on the autism spectrum to the statistic courses I teach in college. It would not make sense because that information does not materially impact my relationship with the students as a professor. However, I might mention that I am very poor at recognizing faces, which explains why I don't recognize my students outside of class, along with a request for them to introduce themselves if they wish to talk with me in the hallway or at my office. The specific characteristic of prosopagnosia or facial recognition is worth mentioning because it directly impacts my relationship with the students. However, this is considered a soft disclosure (Debbaudt, 2001) because I have not mentioned the reason behind the difficulty. My self-advocacy was in asking the students to self-identify outside of class.

A hard disclosure involves my telling the class I have autism. Not appropriate for a statistics class, but very much so for a course in teaching educators how to work with children on the autism spectrum. In these cases, my informing the students of my childhood autism diagnosis is very appropriate because it materially impacts our relationship (Shore, 2004).

Successfully Employing Passions and Using Characteristics of Autism on the Job

Temple Grandin (1999, 2006) and other experts in the field of autism strongly recommend matching employment to passions, strengths, and characteristics. Stephen Shore described how he moved from being a busboy to following his passions:

Although the thought of my being on the autism spectrum never entered my mind [when as a teenager I worked as a busboy in a restaurant], it is clear that some of the characteristics made it difficult for me to perform this job well. The noise of the establishment was overstimulating and there seemed to be an unwritten code of conduct that I was unable to decode and follow. As a result, I would tend to shut down and work slowly, much to the disappointment of my supervisors and myself as well.

Riding and repairing bicycles was a passion of mine at that time and it occurred to me that perhaps I could be more successful earning money as a bicycle mechanic. Shortly thereafter I secured employment repairing and assembling bicycles in a bicycle shop. Bicycle repair served me well all the way through college where I set up my own shop, earning much more money in an afternoon than I could in a work-study position as a security guard or in the dining commons. Had I not gone on to university, then I likely would have become a bicycle shop owner.

This job fit me for several reasons. First, my passion for bicycle repair provided plenty of incentive to do well. Secondly, the social demands placed on a bicycle mechanic are far less stringent than in a large, noisy restaurant, with many employees. Thirdly, a bicycle shop tends to be a much quieter and calmer environment than many other employment situations.

After graduation from my undergraduate degree I found employment in another area of passion—mutual funds in a certified public accounting firm. Even though I had great knowledge of mutual funds and could significantly contribute to a mutual fund audit, I found the social demands of the accounting position with my coworkers was like learning to interact with inhabitants from another planet. People at the company must have felt similarly since I was shortly let go from the position. Interestingly, one of the participants in my exit meeting wondered out loud if I had a disability that I failed to disclose to them. In summary, it's important to consider the social implications of employment in addition to the passions and special interests (Shore, 2004).

There was a discussion in chapter 2 regarding identifying and respecting an individual's passions (reframed from obsessions or narrow range of interest) which could lead to relationship building and career exploration. However, it is not always possible to match a job with someone's passion. Appendix E explains "power cards," in which a passion is incorporated into the work setting to help an individual with ASD deal more effectively with job-related stress.

Strategies to "Support the Supports"

The people who support a person with ASD must also receive aid to continue and enhance their ability to both support and therapeutically fade that support. Strategies include ongoing training, careful matching of staff and individuals, and an effective system of communication that connects all parties (the individual with autism and all the supports) so that pertinent information is shared in a timely manner.

Training should involve topics such as basics on autism/Asperger's, job analysis, and job matching, but should concentrate on the uniqueness of the person being supported: his or her communication style, sensory needs, learning style, and stress management techniques; approaches to avoid when working with this individual; and "early warning signs" to keep problems manageable—basically, an understanding of how to utilize what we know that helps keep a person focused and content on the job. Training should be provided before the staff member works with the individual *and* during the time the staff member is working with the individual. Structure and consistency are very important to the person with ASD. Ongoing training and support for those who provide the support may help reduce staff turnover and thereby provide the person with autism more consistency.

Issues will arise that are unexpected, so an effective communication system that involves all and can react to new concerns in a timely manner is critical. The demands of the job may change; the individual may grow in the job and be ready to consider change; or there may be parts of the job that the individual is struggling with. A good communication network will ensure not only that problems are dealt with effectively, but that

Chapter 4

progress is monitored closely. This monitoring will help to ensure that the supports in place are meeting the individual's needs and to determine if fading of those supports is warranted.

Given the pervasiveness of the needs of people with ASD, it may be helpful to develop a specialist position within the VR office, as has been done for other disability groups (e.g., deafness) and other specialty areas (e.g., workers' compensation). This key person would link with developmental disabilities service providers, transition services, and other systems that could help to support the person with ASD.

Supporting a person with ASD in an employment setting can involve a lot of time, energy, resources, and creativity, but the results are worth it, as this group has been overlooked and underserved for a long time. As a result, society and the workplace have missed out on utilizing the skills and talents of a group of people.

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APPENDIX E

SELF-ADVOCACY AND DISCLOSURE

Developed by Ruth Elaine Hane (2004), the form below can help in deciding whether to disclose, how much to disclose, and when to tell another person about being on the autism spectrum. The top of the form helps you determine if disclosure may be necessary. A rating of 3 or greater indicates that serious thought needs to be put into how you will tell another person.

Disclosure Worksheet	
1-10 Level _____	
Situation:	
<input type="checkbox"/> Tell	<input type="checkbox"/> Not Tell
Possible result:	Possible result:
<input type="checkbox"/> Tell Later	<input checked="" type="checkbox"/> Need Help
Possible result:	<input checked="" type="checkbox"/> Get Help: Name: _____ Phone: _____ Email: _____ Notes:

Disclosure Worksheet	
1-10 Level <u>8</u>	
Situation: My supervisor wants me to move to a different cubicle. It will be noisy and distracting in the new location.	
<input type="checkbox"/> Tell	<input type="checkbox"/> Not Tell
<ul style="list-style-type: none">- that I am easily distracted- that I am sensitive and on the spectrum of autism <p>Possible result:</p> <p>She may pass me over for a promotion next month</p>	<ul style="list-style-type: none">- just move and make the best of it <p>Possible result:</p> <p>Be miserable, may make mistakes, less work from distractions</p>
<input type="checkbox"/> Tell Later	<input checked="" type="checkbox"/> Need Help
<ul style="list-style-type: none">- Try it for week- Say: I'll give it a try, but it may be too noisy for the kind of work I do. <p>Possible result:</p> <p>A week away may be too hard; I may be short tempered.</p>	<ul style="list-style-type: none">- Should I disclose about my autism?- If I do what should I say? <p><input checked="" type="checkbox"/> Get Help:</p> <p>Name: <u>Mary</u></p> <p>Phone: <u>000-000-0000</u></p> <p>Email: <u>mary@friend.org</u></p> <p>Notes: Mary suggests that I try it for one week—call her if I need more help.</p>

Power Cards

The motivating factor behind power cards (Gagnon, 2002) is the employment of a passion or special interest of a person with autism or Asperger's syndrome. Additionally, a hero model is used to provide the needed instruction. Suppose we have a person who tends to act out and be disruptive when he's frustrated at work. This person also has a special interest in airplanes and flying in general. To help him, the job coach or another person would develop a story, which might go like this.

Chuck Yeager Learns to Get Along

Chuck Yeager loves to fly his planes and to talk about when he became the first pilot to break the sound barrier. Sometimes when Chuck does not understand what the traffic controller is telling him, he yells and slams his fist down on the controls of the airplane. However, Chuck has realized that this is not a good way to behave and has come up with some ways to deal with his frustrations that he would like to share with you.

Chuck Yeager wants you to choose one of the following three ways to calm down. If you are still frustrated, you can try another way.

1. Take five deep breaths, exhaling slowly after each one.
2. Close your eyes and slowly count backwards from 10 to 1.
3. Go to a quiet place and look at flying magazines.

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Chapter 5

CHALLENGES AND RECOMMENDATIONS

By Anna Penn Hundley and Ruth Christ Sullivan

Vocational rehabilitation (VR) counselors may be hard pressed to find community programs to which they can make referrals for employment or with whom they can contract for autism-specific training and experienced job coaches. VR counselors who are knowledgeable of autism spectrum disorder (ASD) will be more likely to develop the full potential of individuals with ASD who come to them for assessment and placement in employment.

VR counselors can make a tremendous positive impact on the lives of people with autism in the world of work. It is our hope that this summary of recommendations will be helpful to VR counselors who face numerous systemic and personal challenges while working with people who have ASD (for more detailed information on recommendations, please read chapters 1 to 4).

Systemic Challenges and Recommendations

Systemic challenges are the issues VR counselors may encounter when attempting to adapt the current practices and make these systems work for individuals with ASD.

Challenge 1

Few job coaches have the specialized skills required to support persons with autism. Job coaches may not have training on how to support persons with ASD, and untrained job coaches can lose

Chapter 5

their job while the person with ASD is still employed (Smith, 1990).

Recommendations

VR counselors seeking job coaches should look for these personal attributes:

- Great communication skills
- Intellectual curiosity
- High energy level
- A striving for excellence
- Initiative; being a self-starter
- Respect for the dignity and worth of a person with ASD
- Keen sense of appropriate dress for self and person with ASD, taking into account the culture of the job and community
- Keen sense of grooming and personal hygiene
- Creativity

In addition, VR counselors who find job coaches with these attributes should train them for specific skills:

- General knowledge of characteristics of autism
- Understanding of the “theory of mind” (see Glossary)
- Knowledge of positive behavior supports and how to implement them
- Skill to assess the sensory needs of the person with ASD and to modify the work environment to meet these needs
- Skill to conduct a functional assessment of behavior
- Ability to communicate with the person with ASD
- Ability to support the person with ASD to ensure success on the job
- Ability to use information from a functional assessment of behavior to minimize challenging behavior
- Ability to manage challenging behavior with positive behavior supports
- Ability to coordinate information from a task analysis of the job and needs of the person with ASD to provide the best level of support
- Ability to address employee/employer relations

Job coaches and their supervisors must be knowledgeable regarding the range and type of behavior and challenges faced by the person with ASD in the workplace and must be capable of designing supports that enable success on the job (Department of Public Welfare, Commonwealth of Pennsylvania, 2004). Job coaches must be trained and have first-hand knowledge of the job. It is important to teach the job skill in the setting where the person with ASD will be working. This should minimize the need to generalize from cues in the training setting to cues in the work setting (Smith, 1990).

A job coach who knows and understands the person with ASD is essential to successful job placement (Autism Society of Delaware, 2005). Experienced and qualified job coach trainers should mentor less experienced job coaches. A career path in job coaching should be encouraged and compensated at a higher level. Perhaps the Association of Community Rehabilitation Education could develop a certification for job coaches. Collaboration with programs such as the Commission on Rehabilitation Counselor Certification to mandate ASD training for certified rehabilitation counselor continuing education hours is recommended. Staff support ratios must be individualized and may vary from time to time, depending on life and job circumstances. Job coach support should be faded gradually and systematically. In some cases, continual job coach support may be necessary for long periods if the person with ASD is to maintain employment.

Challenge 2

Few VR counselors have professional training or experience working with persons with ASD. The severe shortage of trained professionals who work with adults with ASD is a significant barrier for training VR counselors.

Recommendations

College and university departments who train VR professionals need to provide coursework and practicum experience in ASD. Federal, state, and regional administrators of VR should provide in-service training for all professional staff in their departments to work with persons with ASD.

Chapter 5

The Rehabilitation and Continuing Education Program should increase training in ASD. A model for training is included in Appendix G. The leadership of VR agencies should conduct in-service training and utilize providers in the community who have experience and expertise working with adults with ASD.

Information on existing community providers in the U.S. can be found at the website of the National Association for Residential Providers for Adults with Autism (NARPAA; www.NARPAA.org).

Challenge 3

VR services are outcome driven and time limited; however, a person with ASD may need lifelong support. Significantly reducing job support may result in job loss for a person with ASD.

Recommendations

The Rehabilitation Services Administration (RSA) should collaborate with other federal agencies to secure funding for the long-term support needed when VR services end. At this time there is no mandate for such a funding arrangement. Medicaid's Home and Community Based Waiver Program will fund job coaches, but as mentioned previously, that support is not mandatory. The lack of funding for long-term support seriously jeopardizes employment for this vulnerable population. The system needs to provide a seamless continuum of services.

Challenge 4

Research information on best practices for employment of persons with ASD is very limited. Most of the current research is being conducted with children.

Recommendations

Universities should collaborate with the public and private sector in the autism community for outcome-based applied research on promising practices for successful employment, such as

- The application of technology using video modeling
- Determination of the best job match
- Social skills training for adults

- Job coach training
- Development of natural supports

Challenge 5

VR counselors' involvement with public schools sometimes does not begin until the person with ASD is about to graduate. Appropriate functional skills for employment may not have been taught.

Recommendations

- A transition plan with the parents/guardian, the individual, the school district, the community disability agency, and the VR counselor should be developed and implemented by age 16 for the person with ASD.
- At age 16 an application for developmental disability long-term funding should be completed and submitted so VR services can start at age 21, or upon leaving school.

Challenge 6

There is a severe shortage of agencies that provide specialized services for adults with autism. Only about 25 agencies in the U.S. provide adult autism-specific services, and most of those agencies are members of NARPAA.

Recommendations

A good choice for a vendor would be an agency that has experience delivering services for adults with autism. For contact information on experienced agencies, go to the www.NARPAA.org website. The Autism Society of America website (www.autism-society.org) is another resource. Websites on autism should include information and links regarding employment of persons with ASD. If autism-specific services are not available in your area, attempt to find a community developmental disability agency that would be willing to be trained in autism. Training should be provided by a specialist in adult autism issues and needs. Use the NARPAA Standards, which are located in Appendix F, for evaluating vendor staff qualifications.

Chapter 5

Given the shortage of knowledgeable vendors, the VR counselor may need to provide case management for the person with ASD.

Challenge 7

This IRI document will be widely disseminated by VR agencies, conference presentations, and online links. We need to ensure that it will have a positive and timely impact for persons with ASD.

Recommendations

- Measure the impact on employment for persons with ASD.
- Determine a baseline from the RSA-911 report (See Glossary) for persons with ASD.
- Periodically review the RSA-911 report over the next 5 years to determine the impact.
- Ensure that websites of autism organizations contain links to the IRI document.
- Review this IRI document in 5 years and update it with current information, then redisseminate the information.
- Develop a network of resources of VR counselors and autism providers. Provide meaningful opportunities for the groups to work together.

Personal Challenges and Recommendations

Personal challenges address the behaviors that may present employment issues for persons with ASD.

Challenge 1

Persons with ASD may be nonverbal or not able to answer the VR counselor's questions during the intake process. For example, in some states, the VR counselor is instructed to ask two questions: How do you think we can help you? and How does your disability make it hard for you to work? (Texas Department of Assistive and Rehabilitative Services, 2005).

Recommendations

During the intake process, have a facilitator present who knows the applicant. This person must be someone that the applicant feels

comfortable with and someone the applicant wants involved in the intake process. If the applicant is nonverbal or cannot answer a question, rephrase the question or allow the facilitator to answer. Determine if the person with ASD has a legal guardian and include the guardian if possible and/or feasible.

Challenge 2

Persons with ASD may have difficulty understanding and engaging in conversation. They

- May be nonverbal or have problems expressing themselves
- May not respond to verbal requests
- May be echolalic
- May have a restricted repertoire of responses
- May be very literal
- May not ask any questions or may ask too many questions
- May not understand nonverbal cues
- May not make direct eye contact
- May need an extension of evaluation time to determine eligibility
- May need trial work with real work experience before closing the case

Recommendations

Consider the social aspects of different job environments when making a job placement. Discuss with coworkers the characteristics and behaviors of people with ASD. Build in natural supports so the person can have someone to go to if there is a problem or a need for clarification.

Communicate information directly and avoid metaphors and idioms, which may be interpreted literally. For example, ask, “How are you today?” rather than “What’s up?” Provide consistency of instruction given by the same person if possible. Do not depend on nonverbal cues—such as telling an individual, “Your job is finished,” standing up to leave, and expecting the person to follow. The person may need a verbal directive such as “It is time to leave the room and go to the second workstation;

Chapter 5

follow me, please.” For the nonverbal person with ASD, use a communication aid such as a picture cue system or some form of assistive device that aids the person with communication. People with ASD often require extra time to process conversation.

Any time a request is made, wait for a response before repeating the statement. Don’t ask a series of questions. Tell the person, using clear, concise, concrete language, what you want him to do. Model the appropriate behavior. Structure, order, routine, and clear rules and assignments are the key to success for a person with ASD (Hurlbutt & Chalmers, 2004; Doyle, 2003).

Challenge 3

Persons with ASD may have difficulty with problem-solving and drawing inferences. They

- May not be able to “read between the lines”
- May appear regimented and have one way of performing a task
- May have unpredictable responses to a change in routine or situation
- May deal with a situation in a concrete manner
- May have difficulty transitioning from one situation to another situation

Recommendations

Secure a job that requires limited problem-solving skills. Provide a job task which, once started, can be finished without interruptions. One example is an assembly job that requires the same steps every time it is performed.

When teaching the job, have the person with ASD restate the directions. Break directions down into simple steps, with time limits delineated for completion of a task. Provide a consistent work station or work set-up. Ensure that the employee knows what to do when the task is finished. Provide regular reminders and positive feedback.

Develop a system for transitioning from one task to another. Be sure that during a break or downtime, the person with ASD has a preferred activity to engage in, such as a video game.

Challenge 4

Persons with ASD may be rigid in their thinking and assume that other people think the same as they do. They

- May have problems with authority figures and may not understand hierarchy
- May be egocentric and have trouble reading other people's behavior in relation to theirs (which is known as theory of mind deficit)
- May organize their world differently (locate their office by some particular object or item rather than an office number)
- May have tunnel focus or concentrate on just one thing and be unable to pay attention to other important details (Shattuck, 2001)

Recommendations

State differences of opinion calmly and in a nonconfrontational manner. Avoid suggestive and indirect language (Myles & Simpson, 2003).

Provide training to coworkers and supervisors in how best to solve a problem. Explain the situation in terms of the problem and not the person (Shattuck, 2001). Attempt to emphasize the concrete aspects of the task, not the big picture. Teach the job right the first time by establishing a routine as quickly as possible. For example, use a pictorial chart of the hierarchy of who to go to if there is a problem (Emmett, 2004).

Challenge 5

Persons with ASD tends to learn social skills without learning their meaning or context (Myles & Simpson, 2003). They

- May lack awareness of the unwritten rules of social conduct

Chapter 5

- May not understand the concept of making small talk (for example, asking a coworker how his weekend was or how he enjoyed a movie)
- May not appreciate the feelings and thoughts of others
- May not realize that a comment would embarrass or cause offense to another person and that a simple apology could help repair the person's feelings (Attwood, 1998)
- May lack emotion or may not use spontaneous gestures, touch, or facial expressions
- May misunderstand humor and sarcasm
- May appear rude and unfriendly (Seltzer & Krauss, 2002)

Recommendations

Social skills that are needed on the job must be trained, just as technical skills are trained. Social skills are critical for successful employment. Two methods for teaching appropriate social skills are role playing and video modeling. All of the references listed in this chapter are excellent resources for teaching social skills.

Discuss with coworkers the individual's response to certain situations, such as lack of eye contact, failure to make small talk, or walking between two people who are talking. Others may perceive these responses as rudeness. However, they should be explained as a common characteristic of autism. Job coaches and other staff must be very consistent in the way they teach the person social behavior necessary for successful employment.

Challenge 6

Persons with ASD may have unusual responses to tactile, olfactory, auditory, and visual stimuli, which may cause difficulty in the work environment. They

- May be distracted or disturbed by different types of sounds, lighting, and smells (Grandin & Duffy, 2004)
- May be negatively impacted by the environmental clutter of a job site

Recommendations

Respect the sensory sensitivities by designing the work area to minimize seriously distracting sights and sounds. For example, allow the individual to wear ear plugs or to listen to his or her choice of music through headphones; use tinted glasses to minimize the effect of fluorescent lighting or other harsh light; have the employee's work station near a window that provides natural light; and if the employee is required to wear a uniform, allow modifications that will make the uniform more comfortable.

A useful technique for self-regulation could include relaxation and deep breathing exercises. Schedule sensory breaks throughout the work day to assist the employee in coping with the busy work environment.

Be sure that the solution to the person's sensitivities is not degrading and does not call undue attention to the problem. Do not sneak up on someone with ASD or startle them. If the person's back is turned, announce yourself. If the person gets too close to you when talking, calmly ask the person to move back a step. A quiet setting out of heavily trafficked areas is usually the best work location for someone with ASD (Grandin & Duffy, 2004). If clutter is a problem, develop a plan (and share it with the person with ASD) to get things organized into neat specific categories. People with ASD are "systemizers," which could be a real asset on a job.

Challenge 7

Persons with ASD may have impaired fine or gross motor skills accompanied by complex body mannerisms. They

- May have compulsions and/or rituals, such as opening a door at a certain angle every time
- May have circumscribed interests and are extremely rigid in their thinking (Seltzer & Krauss, 2002)
- May be clumsy, have problems with pencil grasp, and write illegibly
- May need positive motivation to work—even for the many ASD employees who are well coordinated, with excellent fine and gross motor skills

Chapter 5

Recommendations

Carefully match the job with the individual's interests and skills. Analyze the job and make adaptations using jigs and other prostheses that can help compensate for deficits in fine and gross motor skills. Consult with an occupational therapist who could assist in making accommodations for the individual (Myles & Simpson, 2003).

Build on the compulsions and rituals of the person whenever possible. For example, a person who memorizes the rules of grammar will probably do well in a job requiring coding and classifying books or materials.

Challenge 8

People with ASD typically do not interview well for a job. They

- May not answer the question posed
- May go off on a tangent
- May not maintain eye contact with the interviewer
- May give unrelated answers to questions

Recommendations

Facilitate the interview process with the applicant through role playing. Highlight the applicant's strengths. Have a resume prepared. Practice rote responses and have four or five questions prepared for the interviewer. Assist the person with ASD in planning for and dressing appropriately for the job being sought. If it is a mechanic's job, a suit and tie would not be appropriate (Grandin & Duffy, 2004); however, the person with ASD will not know what is and what is not appropriate dress. In lieu of the traditional job interview, an arrangement could be made for the employer to make available short-term job try-outs, in order to demonstrate the person's abilities and strengths (Hagner, 2005). Three or four different on-the-job try-outs could be helpful in assessing desires and capabilities. A well-trained job coach will make sure that the employer perceives the person with ASD as an asset and helps to ensure that the job will be done as the employer expects.

Challenge 9

Persons with ASD may engage in challenging behaviors:

- Stereotypical behavior such as arm flapping, rocking, or odd verbal noises
- Social peculiarities, social interaction difficulties, and to a lesser degree, aggression and anger (Myles & Simpson, 2003)
- Narrow set of interests

Recommendations

If possible, procure a job with duties that enable the person's challenging behavior to become an asset. For example, an individual who likes to break glass could work in a glass recycling job which requires the employee to toss glass items into a large bin. A person with ASD whose intense interest is putting together a 500-piece jigsaw puzzle would probably be successful in an intricate assembly job.

The employer and coworkers must feel confident that if a behavior problem occurs, the job coach or supporting agency will effectively and efficiently handle the situation with a minimum of worksite disruption. The job coach must systematically identify the problem and then design and implement a solution. Personal networking and the development of ongoing relationships with employers must be maintained. If the person is presently taking medication to assist in controlling anxiety, depression, or any other comorbid condition, make sure assessments are made on a regular basis to ensure that he or she is taking the medications properly.

Challenge 10

Persons with ASD may not respond well to change that may occur on the job. They

- May not generalize skills from one place to another
- May not multitask

Chapter 5

Recommendations

When training a new set of job skills, keep the conditions consistent until the employee is responding correctly on a regular basis. Then gradually fade the instructions and prompts as the employee begins to acquire the skill (Scheuermann & Webber, 2002).

Provide support during transition from one task to another. Doing one task at a time is more suitable for the person with ASD (Grandin & Duffy, 2004).

Scheduled job duties need to follow a predictable pattern. Transitions need to be carefully planned and carried out gradually. When change/exceptions must occur, give the employee with ASD as much notice as possible and explain the change. For example, his desk must be moved. If possible, give him choices in some aspect of the move, like which way his desk faces in its new place. Facilitate generalization of skills by briefly retraining the task in the new work environment (Emmett, 2004).

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APPENDIX F

STANDARDS OF THE NATIONAL ASSOCIATION FOR RESIDENTIAL PROVIDERS FOR ADULTS WITH AUTISM (*Updated 2/19/04*)

Area of need	Autism challenge	NARPAA standard
Funding and services	Autism presents a funding challenge because it is a unique developmental disability requiring intensive and individualized services throughout the lifespan. Funding challenges limit access to programs that specialize in autism-specific services to adults. There is a dearth of professional staff trained in the unique needs of adults with autism.	Funding for adult services is individualized and commensurate with the needs of the person. Service providers have specialized training and recognize that adults with autism are lifelong learners.
Individual rights and responsibilities	Adults with autism have difficulty understanding abstract concepts such as rights and responsibilities.	Adults with autism are offered choices that are meaningful and clear. Service providers teach and support creative, individualized choice-making.
Individualized service planning	Adults with autism have difficulty meaningfully and effectively participating in the development of their service/support plan.	Service providers facilitate a variety of opportunities and experiences for adults with autism, enabling them to make informed choices in the development of their service/support plan.

Area of need	Autism challenge	NARPAA standard
Community access and support	Adults with autism have difficulty understanding community risks and dangers. Access to the community is limited by the unusual behaviors and characteristics of adults with autism. There are insufficient professional resources for adults with autism.	A) Service providers teach and support community living skills in the areas of mobility and safety. B) Service providers accompany adults with autism, as needed, to ensure safe access to all areas of the community.
Residential options	Adults with autism have intense communication, behavioral, socialization, and sensory challenges. These challenges limit their community residential options.	Residential options are tailored to the unique communication, behavioral, socialization, and sensory needs of the person. Adults with autism may require 1:1 ratio to promote safety and an opportunity for personal development.
Employment	Adults with autism need individualized vocational training and job accommodations.	A) Service providers will understand the unique learning styles of adults with autism and will develop individualized vocational plans. B) Service providers will work with the community employers to develop job accommodations for adults with autism.

APPENDIX G

MODEL FOR TRAINING: VOCATIONAL REHABILITATION ISSUES FOR PERSONS WITH AUTISM SPECTRUM DISORDERS

Agenda

1. Some statistics; is there an autism epidemic?
2. Definitions of autism spectrum disorders (ASD)
3. Causal factors
4. Treatments
5. Communication
6. Motor difficulties
7. Sensory sensitivities
8. Social skills
9. Behavioral issues
10. Mental health issues
11. Passions
12. Vocational issues
13. Family issues
14. Supports

Program description: During the past several years there has been an enormous increase in the identification and diagnosis of individuals with ASD. This program will explore some of the reasons for this change and why it is significant for the field of vocational rehabilitation (VR). Participants will gain an increased awareness of the complexities of this group of disorders and will learn ways to support someone with ASD. Special emphasis will be placed upon Asperger's syndrome.

This program is designed for: VR counselors, rehabilitation assistants, and supervisors.

Length: The program can be modified to run for a half day, a full day, or 2 full days depending on the needs of the agency requesting the training.

Format: Lecture, small group discussions and exercises, large group discussions and exercises, case studies.

Chapter 5

Learning objectives:

- To increase knowledge of ASD
- To develop strategies to help support an individual with a diagnosis of ASD

Program outline:

- Background: definitions, prevalence, why VR professionals need to understand ASD
- Cause and treatments
- Communication and behavioral issues
- Valuing passions
- Social skill issues
- Strategies to support someone with ASD—with an emphasis on vocational aspects

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APPENDIX H

GLOSSARY

Activities of daily living (ADL): Basic tasks of everyday life, such as eating, bathing, dressing, and toileting.

Asperger's syndrome (AS): A neurobiological disorder characterized by normal intelligence and language development but autistic-like behaviors and marked deficiencies in social and communication skills. Asperger's syndrome is addressed in the DSM-IV.

Association of Community Rehabilitation Education (ACRE): An organization of trained and educated community rehabilitation personnel.

Autism Society of America (ASA): An organization that promotes education, awareness, and advocacy on critical issues related to ASD (www.autism-society.org).

Autism spectrum disorder (ASD): Also known as pervasive developmental disorder (PDD), a disorder that causes severe and pervasive impairment in thinking, feeling, language, and the ability to relate to others. ASD ranges from a severe autistic disorder and pervasive development disorder not otherwise specified (PDD-NOS) to a much milder Asperger's syndrome. Also included are Rett's syndrome and childhood disintegrative disorder.

Basic living requirements (BLR): A table of net income and liquid assets used to determine if an individual with a disability must participate in the cost of services (Texas Rehabilitation Manual).

Center for Medicare and Medicaid Services (CMS): A government agency that serves Medicare and Medicaid recipients by providing resources, outreach, and low-cost health insurance.

Chapter 5

Certified rehabilitation counselor (CRC): A professional who can plan and deliver rehabilitation services for individuals with disabilities. The CRC provides case management, client assessment, service planning, rehabilitation coordination, job analysis, job development/placement, and advocacy.

Childhood Autism Rating Scale (CARS): A diagnostic tool that rates 15 specific items to determine if the individual tested falls within the autistic range: mild to moderate autism and/or severe autism.

Clear and convincing evidence: Facts supporting the notion that an applicant is incapable of benefiting from vocational rehabilitation services in terms of an employment outcome due to the severity of the applicant's disability.

Commission on Rehabilitation Counselor Certification (CRCC): A group that sets the standards for quality rehabilitation counseling services and provides certification for rehabilitation counseling in the United States and Canada.

Department of Health and Human Services (DHHS): The U.S. government's principal agency for protecting the health of all Americans and providing essential human services such as current information and resources regarding diseases, safety, policies, grants, disasters, emergencies, families, children, and foods and drugs.

Department of Rehabilitation Services (DRS): The U.S. government agency that collaborates with other sectors to provide and advocate for the highest quality services that allow individuals with disabilities to maximize their employment, independence, and inclusion.

Developmental disability (DD): A severe, chronic disability, either mental or physical, that manifests by age 22, is perpetuated throughout the lifespan, poses limitations in areas of basic functioning, and requires lifelong care.

Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV): A manual published by the American Psychiatric Association that provides diagnostic criteria for the most common mental disorders. It also describes the disorder and includes information on diagnosis, treatment, and research findings.

Dictionary of Occupational Titles (DOT): A publication of the U.S. Department of Labor that lists most job titles and provides information on the physical demands of each job, including the variety of tasks and the levels of exertion and duration. The ability to perform these tasks successfully defines the minimum physical requirements for a specific occupational title.

Gilliam Autism Rating Scale (GARS): A diagnostic tool used to identify, diagnose, and estimate the severity of the disorder from ratings on four subtests: stereotyped behaviors, communication, social interaction, and developmental disturbances.

Group Action Planning (GAP): Planning by a group to list and achieve designated goals for an individual with a disability. GAP includes having support, making connections, establishing expectations, solving problems, and making progress as a team.

Habilitation: Lifelong support.

Health Insurance Portability and Accountability Act (HIPAA): National standards to protect the privacy of personal health information.

Home and Community Based Waiver (HCBW): A Medicaid program used to fund services not otherwise authorized, such as respite care, home modifications, nonmedical transportation, case management, and personal assistance services.

Impairment-Related Work Expenses (IRWE): Work expenses due to a disability that can be used as a deductible and reimbursed.

Chapter 5

Incidental teaching: An interaction between an adult and child that occurs in a natural situation and is used to give the child an opportunity to practice a skill.

Individual education plan (IEP): A plan that identifies the student's specific learning expectations and outlines how the school will address these expectations through appropriate special education programs and services.

Individualized plan for employment (IPE): A plan that identifies the job and lists the steps and services necessary to achieve employment.

Individuals with Disabilities and Education Act (IDEA): A U.S. law established to improve the quality of life for infants, toddlers, children, and youth with disabilities.

Institute on Rehabilitation Issues (IRI): A national forum for discussing important challenges facing the state-federal vocational rehabilitation programs and the community rehabilitation program partners that is followed by a publication used in training.

Job coaching: Guidance in vocational decision-making such as job identification, skills training, job placement, support, supervision, and postemployment follow-up services.

Knowledge, skills, abilities (KSA): Attributes required to perform a job, such as service, education, or training.

Making Action Plans (MAPS): A person-centered planning process that involves important individuals in a child's life to create a map for achieving set goals.

Memorandum of understanding (MOU): A document that creates the conditions for bringing needed services into local schools as service settings which often prove most convenient to persons with disabilities and their families.

National Association for Residential Providers for Adults with Autism (NARPAA): An organization created to ensure the availability of residential services and continuity of care (www.NARPAA.org).

Obsessive-compulsive disorder (OCD): An anxiety disorder characterized by recurrent, unwanted thoughts (obsessions) and/or repetitive behaviors (compulsions).

Office of Special Education and Rehabilitation Services (OSERS): A U.S. government entity that provides leadership and financial support to help states and local districts serve infants, toddlers, children, and youth with disabilities through the age of 21.

Person-centered planning (PCP): Planning that involves building services tailored to the individual with a disability or an involved family member.

Picture exchange communication system (PECS): An augmentative communication system developed to help individuals quickly acquire a functional means of communication.

Plan for Achieving Self-Support (PASS): A work incentive allowing individuals with disabilities to set aside income and resources for employment investments and work expenses that is designated as a step toward financial independence.

Planning Alternative Tomorrows with Hope (PATH): A process for developing goals as a team to address the short- and long-term needs of a child.

Positive behavior support (PBS): An empirically validated, function-based method used to eliminate challenging behaviors and replace them with pro-social skills.

Postsecondary education: Education beyond high school, including vocational and career schools and 2- and 4-year colleges and universities.

Power cards: A tool or technique that promotes the use of an individual's special interests to engage him or her in work, activity, or learning.

Rehabilitation and Continuing Education Program (RCEP): A program that provides continuing education services to rehabilitation organizations and personnel in the state vocational rehabilitation agencies.

Chapter 5

Rehabilitation Services Administration (RSA): A U.S. government agency that oversees grant programs that help individuals with physical or mental disabilities obtain employment and independence.

Rehabilitation: Maximum support for a designated period of time.

RSA-911, Case Report Service: Data submitted by state vocational rehabilitation agencies that report all case closures in a fiscal year.

Self-advocacy: The process of reducing societal barriers through full inclusion of persons with disabilities in the community.

Social coach or mentor: Someone who can help the individual prepare for social activities through planning and role playing.

Social Security Disability Insurance (SSDI): A benefit paid to individuals who have worked and paid Social Security taxes (insured individuals).

Social story: A presentation of appropriate social behaviors in the form of a story.

Status 26: A successful case closure.

Status 28: A case in which an individual started a service plan but did not complete the plan.

Status 30: A case in which an individual who is eligible for a service plan did not start the plan.

Supplemental Security Income (SSI): A federal income supplement program funded by general tax revenues (not Social Security taxes) that provides cash to meet basic needs for food, clothing, and shelter for individuals who have little or no income.

Supported employment: Employment that facilitates competitive work for individuals with disabilities and provides ongoing support services in order to perform the job.

Test of Nonverbal Intelligence (TONI): A test that measures nonverbal analogical reasoning, categorical classifications, and sequential reasoning in two different contexts: pictures of familiar objects and geometric designs.

Theory of mind: The notion that individuals with autism do not understand or have difficulty understanding that other people have their own plans, thoughts, and points of view.

Ticket to Work and Self-Sufficiency Program (TTW):

Employment program for people with disabilities interested in working.

Transitional individualized education plan: A plan emphasizing that students with disabilities are to be prepared for employment and independent living.

Trial work experience (TWE): The process of providing assessment and related vocational rehabilitation services to an applicant with significant disabilities.

Vocational rehabilitation (VR): Employment program for people with disabilities.

Vocational Rehabilitation Act of 1973 (Title VI): Federal legislation that authorizes the formula grant programs of vocational rehabilitation, supported employment, independent living, client assistance, training and service discretionary grants administered by the Rehabilitation Services Administration, research activities administered by the National Institute on Disability and Rehabilitation Research, and the work of the National Council on Disability. The Act also includes a variety of provisions focused on rights, advocacy, and protections for individuals with disabilities.

Work Incentive and Improvement Act of 1999 (WIIA):

Legislation designed to remove many of the barriers that previously influenced people's decisions about going to work because of the concerns over losing health care coverage.

Work Incentive Network (WIN): Any agency that takes responsibility for the actual delivery of services or the coordination/referral of services collaborating to combine resources to serve Ticket-holders.

Chapter 5

Work Investment Act (WIA): A federal program that offers a range of workforce development activities that benefit job seekers, laid-off workers, youth, incumbent workers, new entrants to the workforce, veterans, persons with disabilities, and employers through statewide and local organizations.

Work Investment Region/Area (WIR/WIA): Local workforce investment areas (LWIAs) administer WIR/WIA services as designated by the governor, who considers location, population, and commonality of labor market areas.

STUDY QUESTIONS

Chapter 2

1. Transition planning with individuals with ASD works best when it is a collaborative effort involving the student, families, and professionals and ideally is begun later in the academic career, when there is more information about the student's capabilities and needs.
True False
2. Jeffrey is a student with ASD graduating from high school next June. He is currently in a training position learning to do stocking for a grocery store that will consider hiring him as a part-time employee. Jeffrey is not always cooperative about work, and his family wonders if it is worth the effort. Outcome research suggests that
 - a. Jeffrey's behavior should be the focus of efforts after graduation before attempting paid employment.
 - b. Jeffrey has a 70% chance of not being gainfully employed throughout his life if he does not transition into employment after high school.
 - c. There is at least a 70% likelihood that Jeffrey will fail at his first job after high school.
 - d. Individuals with ASD are never successful with employment.
3. Employment is not an important transition goal for most individuals with ASD.
True False
4. Financial planning is essential to a transition plan for individuals with ASD because
 - a. There are issues with eligibility for benefits such as Medicaid and Supplemental Security Income.
 - b. The long-term residential and employment supports for adults with ASD are costly.
 - c. Families may initially find the notion of using federal subsidies distasteful.
 - d. All of the above.

Study Questions

5. Although the transition plan for a student with ASD is lengthy and covers many areas of life function, fortunately the issues are quite similar among all individuals on the spectrum, allowing use of a common, “one-size-fits-all” template.
True False
6. If guardianship is not obtained by the age of majority, a young adult with ASD automatically becomes an independent adult.
True False
7. For intake with a new student consumer with ASD, the VR counselor will get the most useful history and develop the most important connections by meeting:
 - a. Primarily with the student
 - b. With family members close to the student
 - c. With the individualized education program team
 - d. With other adult service providers
 - e. A and B
 - f. B, C, and D
8. Parents of children with ASD report stress levels beyond the high levels of depression and anxiety identified by parents of children with other intellectual disabilities (e.g., mental retardation, Down syndrome), and this affects the transition experience.
True False
9. Families of students on the autism spectrum have low expectations for their child and are always receptive to good advice from professionals.
True False
10. When a young adult consumer has ASD, the VR counselor can anticipate that others in the family may have features of the disorder such as anxiety, depression, deficits in executive function, or deficits in social communication.
True False

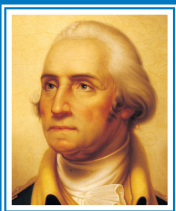
Chapter 3

1. Agencies providing VR services have been effective at finding and serving adults with autism.
True False
2. All individuals who are diagnosed with autism will require some form of assistance with social interactions on the job.
True False
3. Standardized assessments and a traditional work assessment approach alone are useful for young adults with autism.
True False
4. Individuals with autism will very likely need lifelong employment support.
True False
5. Employment is difficult for people with autism because of (circle any that apply):
 - a. Anxiety in new or changing situations
 - b. Difficulty with interpersonal skills
 - c. Inability to learn
 - d. Need for additional staff
6. A person-centered planning approach is (circle one):
 - a. A mandatory process to understand persons with autism
 - b. An initial step in an assessment process
 - c. A way to identify specific vocational skills
 - d. A way to look at the whole person, not just vocational skills
7. When assessing the vocational skills, interests, and needs of a person with autism, the counselor should ask others who know the person for their input.
True False
8. If a person who has autism will not look at you during an interview, he or she needs to learn that skill in order to interview with an employer.
True False

Study Questions

9. If an individual with autism doesn't respond to a question, he or she probably won't and the counselor should just go on to the next question/topic.
True False
10. A job environment that will be a match for many people with ASD is (circle all that apply):
- a. One that has lots of sensory stimuli and a busy atmosphere
 - b. A culture where coworkers are encouraged to collaborate
 - c. A supervisor who maintains rigid expectations and expects employees to be independent
 - d. A routine with opportunities for flexibility as needed

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